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**Siblings' Experiences of having a Brother or Sister with an Eating
Disorder:**

A Qualitative Exploration

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Doctorate in Clinical Psychology

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1. Thesis Abstract

Background: Family members of people with eating disorders are often involved in caregiving. To better understand the impact on them, outcomes such as burden, distress, and less frequently quality of life (QoL) are taken into consideration. Despite advancements in the knowledge base surrounding the experiences of adult and parental caregivers of individuals with eating disorders, particularly Anorexia Nervosa, there is a scarcity of qualitative exploration from the sibling perspective, particularly that of adolescent siblings. **Objectives:** The systematic review aimed to identify research and synthesise findings relating to informal caregivers' quantitative ratings of quality of life in the context of eating disorders. The primary study aimed to explore in detail the lived experience of adolescent siblings with a brother or sister with Bulimia Nervosa or Eating-Disorder-Not-Otherwise-Specified. **Method:** Applying *a priori* inclusion and exclusion criteria to papers identified from a combination of systematic searches of electronic databases and hand searches of other pertinent literature, revealed eight studies to be included for review. Within the qualitative study, eight semi-structured interviews were carried out with siblings (aged 12-19-years) who had a brother or sister with an eating disorder. An interpretative phenomenological analysis approach was utilised to analyse interview data. **Results:** The review highlighted low ratings for aspects of quality of life for informal caregivers of individuals with eating disorders, and some emerging comparative and subgroup differences. Three super-ordinate themes emerged from the qualitative exploration: Sibling Identity, The Vulnerable Social 'Self', and Intra- and Inter-Personal Coping. **Discussion:** Overall the findings provide particular insight into the quality life of informal caregivers and the unique experiences, feelings and various roles of adolescent siblings of people with eating disorders. Implications regarding caregiver support and the needs of siblings specifically are considered. Strengths and limitations, as well as future research possibilities are outlined for both the systematic review and empirical study.

2. Thesis Outline

The following information provides a brief summary of the main chapters of the thesis:

Chapter 3 is a systematic review of the literature pertaining to the Quality of Life of informal caregivers of individuals with eating disorders. This is written in the format of International Journal of Eating Disorders (see Appendix A for Journal Author Guidelines). Initially, 3.2 *Introduction* explores the rationale for the review question and outlines the aim of the review. The systematic search strategy, alongside a flow chart illustrating the steps of the literature search process is contained within section 3.3 *Method*. The characteristics of the studies included for review are presented in section 3.4 *Results*, prior to appraisal and critical examination of the literature. Finally, 3.5 *Discussion* offers a summary of the overall findings, strengths and limitations of the current review and consideration of implications for research and practice.

Chapter 4 presents a research article for the qualitative study aspect of the thesis exploring siblings' experiences of having a brother or sister with an eating disorder. This takes the format of Qualitative Health Research (see Appendix C for Journal Author Guidelines). Within this, section 4.2 *Introduction* provides the relevant research that has guided studies to begin to consider the sibling experience and explores specific literature pertinent to the development of the present study's rationale and aims. The intention of section 4.3 *Method* is to transparently outline in detail the complete methodological process of this study. It is divided into a number of subheadings to facilitate reading including: 1) design and theoretical foundation, 2) recruitment and participant sample, 3) interview schedule and procedure, 4) transcription and analysis and lastly, 5) consideration of quality and reflexivity, with ethical issues considered throughout. Section 4.4 *Findings: The Sibling Experience* presents the super-ordinate and sub-themes within these which emerged from the analysis. These are

illustrated for the reader with verbatim extracts from the data alongside the researcher's interpretations, producing an oscillating pattern of movement between the participant's sense making and the researcher's attempts to make sense of this. Finally, discussion of the findings in the context of relevant literature, and implications for clinical practice and future research, will be considered in section 4.5 *Discussion*. Importantly, within this section there will also be recognition of the limitations of the present study, ensuring transparency for the reader when contemplating and evaluating the findings of this qualitative exploration.

Following this, Chapter 5 provides complete *references* for this thesis as a whole, and finally, the thesis ends with an *appendices* section in Chapter 6. This includes copies of the relevant journal author guidelines, ethical approval documentation, material used during the qualitative study such as the interview schedule, as well as samples of analysis. The inclusion of these types of documents allows the opportunity to provide additional context and clarity of specific aspects of the research process, out-with the body of the main text of the thesis.

3. Systematic Review

How do Informal Caregivers of Individuals with Eating Disorders rate their Quality of Life? A Systematic Review of the Literature

3.1. Abstract

Objective: Recent reviews have explored and promoted a better understanding of caregiver burden and distress in the context of mental health problems and eating disorders; however, the ratings of Quality of Life (QoL) in informal caregivers of individuals with eating disorders have not been specifically reviewed.

Method: A systematic search of five major databases (CINAHL, Cochrane Library database, EMBASE, Medline, PsycINFO) was carried out up until April 2014, in English language only, against *a priori* inclusion and exclusion criteria focusing on quantitative ratings of quality of life. Hand-searching of two relevant eating disorder peer-reviewed journals, reference lists and thesis databases supplemented the searches.

Results: Eight studies fulfilled the inclusion criteria for review, with key information from each study extracted and tabulated. The identified research papers were appraised for conformity in relation to the STROBE statement guidelines for observational studies.

Discussion: Overall the findings from a limited number of reviewed papers tentatively suggest that quality of life ratings of areas particularly related to mental health are low for informal caregivers of people with eating disorders. Findings from a narrower range of included papers indicated lower quality of life than normative reference groups. There was not enough subgroup data to explore gender differences. The findings are considered in the context of the limitations of the papers, as well as the limitations of this review. Future research needs are suggested, including more detailed exploration of the relatively overlooked sibling informal caregivers.

Key Words: carer; eating disorders; informal caregiver; quality of life; systematic review

3.2. Introduction

3.2.1 Informal Caregiving in Eating Disorders

Eating disorders (ED) are often treated in community settings, with NICE (2004) guidance recommending initially out-patient treatment. This means family members may need to assume a caregiving role with individuals with EDs, which can contribute to practical demands, strain on family functioning, and burn out and psychological distress among carers (Graap, Bleich, Herbst, Trostman, Wancata, & Zwaan, 2008; Zabala, MacDonald, & Treasure, 2009). As family based therapies are often recommended interventions for EDs, parents, partners and also siblings are frequently included in treatment. This may require them to provide additional support and caregiving, and increased contact time with the person with the ED, which has sometimes been associated with higher levels of negative caregiving experience (NICE, 2004; Winn et al., 2007). For some family members, being involved in therapy can be one of the most challenging life experiences they encounter, and often the impact on family caregivers, particularly in the context of mental health problems, can be overlooked; though this is becoming a more prominent research area (Brown, 2011; as cited in Hopf, LeGrange, Moessner, & Bauer, 2013; Zabala, MacDonald, & Treasure, 2009)

The term carer or caregiver can be ambiguous, and debate over the definition of this and ‘caregiver burden’ appears to be long-standing (e.g. Platt, 1985). The World Health Organisation (WHO) has recently defined *caregiver* as any individual who “provides support and assistance...with various activities to persons with disabilities or long-term conditions...This person may provide emotional or financial support, as well as hands-on help with different tasks...” and *caregiver* burden is defined as in relation to “family members, friends or other individuals involved with the individual outside the health care system” (WHO, 2004, p.12). However, it is recognised and acknowledged by the Department

of Health (DoH) Carers Strategy that not all carers wish to define themselves as such, but rather as firstly parents, spouses or friends (DoH, 2010). Informal caregiver (IC) is often used in literature when pertaining to a wide range of family members and friends with caring responsibilities, therefore ICs will be the term used hereafter in this review.

Psychological distress, burden and psycho-social functioning of ICs have been well documented for family members of people with physical health problems, for instance in reviews of young people with siblings with cancer (Alderfer, Long, Lown, Marsland, Ostrowski, Hock et al., 2010), and caregivers of a family member with dementia (Etters, Goodhall, & Harrison, 2008), as well as more recent exploration of caregivers' quality of life (QoL) in the context of mental health problems, such as OCD (Grover, & Dutt, 2011). There are also a growing number of studies exploring, both qualitatively and quantitatively, the specific experiences of ICs of individuals with EDs, typically including a combination of Anorexia Nervosa (AN), Bulimia Nervosa (BN), eating disorders not otherwise specified (EDNOS) and Binge Eating Disorder (BED). This is pertinent, as EDs can pose their own particular challenges for ICs as they tend to persist for long durations, with an average course reported as approximately 5-8years. Furthermore, as their onset is often during adolescence, greater caregiving responsibilities may fall to parental and sibling ICs (Martin et al., 2011; NICE, 2004).

Qualitative interviews with parental caregivers revealed an array of social, practical and emotional implications such as financial concerns, social isolation, stigma, and depletion of their coping resources (Hillege, Beale, & McMaster, 2006). Conversely, some positive caregiving experiences have also emerged, for example, increasing personal strength and more understanding of themselves and others (e.g. Perkins, Winn, Murray, Murphy, & Schmidt, 2004). Another study reported that ICs had a higher levels of distress than ICs of adults with psychosis although the authors acknowledged problems with how well the groups

were matched, while others found that 36% of their IC sample reported significant psychological distress indicative of mental health difficulties (Treasure, Murphy, Szmukler, Todd, Gavan, & Joyce, 2001; Whitney, Haigh, Weinman, & Treasure, 2007). In addition, QoL judgements have also been shown to be worse for ICs than for their equivalent general population, although this sample was not specifically ICs of EDs (Fleishmann and Klupp, 2004; as cited in Martin et al., 2013). A recent systematic review appraising studies of ICs in families of people with EDs by Zabala et al. (2009) found high levels of anxiety and depression, scores over thresholds for ‘caseness’ for psychological distress, and high subjective burden. This review did not, however, assess the quality of the papers included for review, or consider another aspect of IC wellbeing, their QoL ratings, as has often been included in reviews with the clients with EDs themselves (showing lower perceived QoL), or in ICs of individuals with other physical and mental health problems (Alderfer et al., 2010; Engel, Adair, Las Hayas, & Abraham, 2009; Hay & Mond, 2005; Grover & Dutt, 2011). Recent studies have investigated QoL outcomes in ICs of people with EDs, with De La Rie et al. (2005) appearing to be one of the first, and have indicated low QoL ratings, making this an important outcome to investigate not only for the individual with the ED, but also their IC. However, as Martin et al. (2011) stated, some of the extant literature can be limited by the inclusion of AN diagnoses only, impacting on generalizability to ICs of individuals with other types of EDs, or by appearing to measure burden more generally rather than specifically QoL.

3.2.2 What is and How to Measure Quality of Life

There is often difficulty defining outcomes for ICs, as there can be varying interpretations of QoL (Platt, 1985; Chow, Morrow, Robbins, & Leask, 2013). The WHO definition of QoL is “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and

concerns” (WHOQOL Group, 1998 p.551). Dimensions can include physical function, social activity, emotion wellbeing and general life satisfaction, meaning it is a broad construct but is widely used in research literature and previous reviews (Chow et al., 2013; Engel et al., 2009; WHO, 2004). A number of QoL measures are available, such as the WHOQOL-BREF (WHOQOL Group, 1998) and the Short Form Health Survey-36 or 12-item (SF-36: Ware & Sherbourne, 1992; SF-12: Ware, Kosinski, & Keller, 1996) among others, in addition to single item questions or Likert scales. A comprehensive review of IC outcome measurements noted that no specific robust, validated measure could be identified to be recommended for use with ICs; however, the use of generic instruments, despite not having been developed specifically for ICs, appear to be deemed appropriate and often used in research with ICs in physical- and mental-health contexts (Argimon, Limon, Vila, & Cabeza; 2004; Harvey, Catty, Langman, Winfield, Clements, Burns et al., 2008). It was acknowledged that although the development of some caregiver-specific measures and ED condition-specific measures are emerging, further testing of their psychometric properties is required before being used routinely in practice (Harvey et al., 2008).

Overall the impact of mental health problems, including EDs, on ICs appears significant. QoL, rather than burden or wellbeing more generally, in individuals with EDs and in ICs of individuals with other physical and mental health problems has been previously reviewed; however, to the author’s knowledge, ratings of QoL for ICs in the context of exclusively EDs have not been systematically reviewed.

3.2.3 Aim of Review

The purpose of this review was to systematically review the existing research regarding the self-reported ratings of QoL in ICs of individuals with EDs, as measured by quantitative QoL instruments.

3.3. Method

3.3.1 Inclusion and Exclusion Criteria

Participants: No restriction was placed on age, gender or nationality of ICs of individuals with eating disorders as a limited number of available papers involving this population was anticipated. ED included a reported *diagnosis* of AN, BN, EDNOS and BED. The term caregiver was based on the definition by WHO (2004) as outlined in 3.2.2.

Outcomes: Any quantitative measure of QoL was considered for inclusion, with the exception of a single-item measure (e.g. a 0-10 rating scale). As reported above, Harvey et al. (2008), in a review of instruments to measure outcomes for carers of people with MH problems, outlined that there has been no preferred standard tool with robust psychometric properties consistently recommended for use with carers. Therefore, tools originally designed to measure *client or general population* QoL are often used with ICs in research, and so were included in this review. Additionally, as there was no restriction on age of ICs, the validated PedsQL measure was included as this may have been utilised in studies with ICs under 18.

Study Design: Due to the nature of the review question it was anticipated that observational studies would be prominent, including cross-sectional, case-control and cohort studies. However, other types of studies such as Randomised Control Trials (RCTs) were also considered for inclusion if they reported QoL in ICs. Single case studies were excluded due to issues with generalizability and increased bias, and studies appearing to use duplicate data were excluded. For the aims of this review, when multiple sets of data were included in papers, only baseline or pre-intervention data were used (c.f. Zabala et al., 2009).

Language: A lack of translation resource available to the reviewer, limited the search to English language studies only.

3.3.2 Literature Search Strategy and Study Selection

Prior to conducting literature searches, the Centre for Reviews and Dissemination (CRD) database was searched, which revealed no recent similar reviews had been carried out. The following electronic databases were searched from start dates until April 2014: CINAHL (1937-April 2014), Cochrane Library (start date-April 2014), EMBASE (1980-April 2014), Medline (1966-April 2014) and PsycINFO (1987-April 2014). The search terms utilised were: (carer*.af. OR caregiver*.af. OR parent*.af. OR sibling*.af. OR (family adj care*).af.) AND ((quality adj of adj life).af. OR *QoL/.af. OR HRQoL.af. OR PedsQL.af. OR wellbeing.af.) AND ((eating adj disorder*).af. OR anorexia nervosa.af. OR bulimia nervosa.af. OR "binge eating disorder".af. OR (eating disorder not otherwise specified).af.). Thesaurus and 'map terms' functions within databases, key terms from other reviews in related areas, as well as discussion with the second author of this review, were considered when generating the search terms. The search of the five databases yielded 1,984 papers, and following removal of 703 duplications this left 1,281. Of these, 1,252 were then excluded during a screen of the titles and/or abstracts, leaving 29 papers to be read in full. The application of the *a priori* inclusion/exclusion criteria by the first author resulted in a further 24 papers being excluded, leaving a total of 5 papers for inclusion in the review.

A hand search (start dates-April 2014) of peer-reviewed International Journal of Eating Disorders and European Eating Disorders Review was also carried out identifying 6 additional papers, of which 1 fulfilled the inclusion criteria. In addition, grey literature searching and review of the reference lists of the included papers revealed 2 unpublished thesis manuscripts, culminating in a total of 8 papers to be included in the systematic review. A flow chart illustrating the literature search and study selection process can be seen in Figure 3.1.

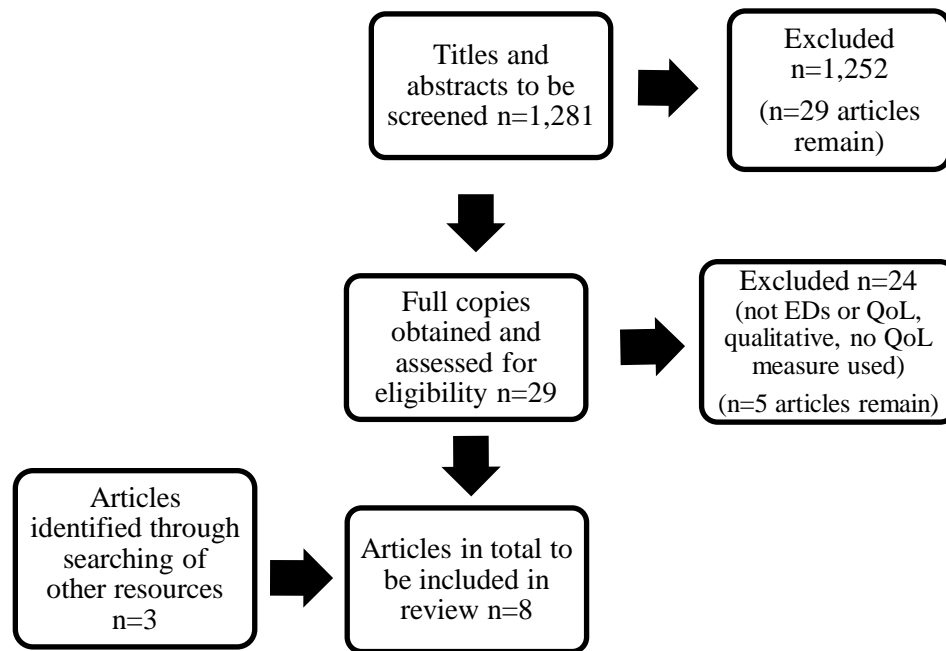


Figure 3.1 Flow chart illustrating the literature search process

3.3.3 Study Appraisal

Study quality can be a subjective construct; therefore more formal approaches to quality assessment have been developed and although these remain subject to bias they are becoming common place, particularly for randomised control trials (RCTs; Deeks et al., 2003). Within non-experimental studies, two recent reviews have acknowledged a scarcity of attention to the development of quality assessment tools for observational studies and concluded there is no single tool most recommended for use to assess quality (Jarde, Losilla, & Vives, 2012; Sanderson, Tatt, & Higgins, 2007). Given this context, the STROBE statement (a 22-item checklist; von Elm et al., 2007), although originally developed as a *reporting* (opposed to *methodological*) quality guideline for observational research, has been described as a suitable starting point for consideration of the critical domains to be considered and is often endorsed in the field of health, perhaps given its extensive development process and inclusion of items seemingly associated with susceptibility to bias (Jarde et al., 2012; Sanderson et al., 2007). Therefore, conformity to the STROBE statement guidelines for observational studies of each individual article was included in the review (for guidelines see Appendix B). A Yes/No

judgement was made for whether each of the 22-item recommendations were included, which covered 6 areas including Title and Abstract, Introduction, Methods (with sub-items of ‘participant selection’ and ‘bias’), Results (including ‘non-participation’ and ‘confounder’), Discussion (taking into account limitation), and Other Information (encompassing consideration of any implications of funding). See Vandenbroucke, von Elm, Altman, Gotzsche, Mulrow, Pocock et al. (2007) for detailed explanation of each recommendation.

3.4. Results

A summary of the 8 articles included in the review is presented in Table 3.1, alphabetically, a narrative synthesis then follows.

3.4.1. Characteristics of Included Studies

Overall the research reviewed was diverse: five studies had cross-sectional designs (*Areemit et al., 2010; De La Rie et al., 2005; Linacre, 2011; Martin et al., 2011; Raenker et al., 2013*) which utilised the PedsQL, WHOQOL-Short Version, SF-36 or SF-12. One was a prospective cohort study employing SF-12 (*Las Hayas et al., 2014*), and the other two studies were small RCTs with SF-12 or SF-36 as outcome measures (*Hoyle et al., 2013; Yu, 2008*). Sample size ranged from n=20 to n=252 with half of the studies recruiting <40 ICs; in total across the eight studies 836 ICs participated and 61% were female. One study included parents (mothers) only (*Yu, 2008*), one siblings only (*Areemit et al., 2010*), and the remaining six studies involved variations of multiple ‘types’ of ICs (i.e. parents, partners, siblings, children, friends).

Across the studies 598 patients (95.6% female) with EDs linked to the ICs were involved; AN diagnoses were the exclusive focus of two studies (*Hoyle et al., 2013; Raenker et al., 2013*), whereas the others had a mixture of AN, BN and EDNOS, with only one of these six including BED (*De La Rie et al., 2005*).

Table 3.1 Characteristics of included studies

<i>Author, year, country</i>	<i>Study design</i>	<i>Caregiver Characteristics</i>	<i>Patient with ED Characteristics</i>	<i>Measure of Quality of Life</i>	<i>Key Findings</i>	<i>Database</i>
1.Areemit et al. (2010) Canada	Cross-sectional	20 siblings (14 female, 6 male) Mean age = 13.7 years (SD = 2.06)	n=17 (13 AN, 4 EDNOS) (15 female, 2 male) Mean age = 14.5 years (SD=1.8)	PedsQL	The siblings' average QoL was above the cut-off point (1SD below US population mean) for risk of impaired QoL in all (4) domains, and total and summary scores. However 6/20 siblings did score below the cut off points.	PsycINFO
2. De La Rie et al. (2005) Netherlands	Cross-sectional (with comparison data)	40 parents/ siblings/partners (25 female, 15 male) Mean age = 46.0 years (SD = 10.7)	n=40 (29 AN, 7 BN, 2 BED, 2 EDNOS) Gender = NR Age = NR	SF-36	Compared to a retrospective Dutch normative reference group (n=1742) caregivers in EDs reported significantly lower scores on 4 of the 8 SF-36 scales. With 2 of the 8 scores higher and no significant difference for 2 of the other 8 scales.	PsycINFO
3. Hoyle et al. (2013) UK & Australia	RCT of web-based skills intervention for ED carers	37 family-member carers (33 female, 4 male) Analysed 18 = online intervention, 18 = online intervention + guidance Age = NR	n=17 (17 AN) Gender = NR Age = NR	SF-36	No difference in baseline / pre-intervention ratings between carers in the 2 groups on one SF-36 score.	PsycINFO
4. Las Hayas et al. (2014) Spain	Cohort (2-year follow-up) (with comparison data)	109 parents , partners, sibling /child (59 female, 50 male) Mean age = 49.35 years (SD = 11.73)	n=69 37 AN, 13 BN, 19 EDNOS (69 female) Mean age = 25.88 (SD=9.5)	SF-12	Caregivers presented low scores on SF-12 at T0 and T1 for MCS (T2=high attrition). Significant differences in mean scores for MCS between caregiver responders and non-responders at baseline, worse for responders. In comparison to a Spanish normative sample scores, caregivers scored significantly lower for MCS only at all time points.	EMBASE

5. Linacre (2011) UK	Cross-sectional (with comparison data)	104 parents, siblings, spouse, friends (76 female, 28male) 18-30years=6 31-40years=7 41-50years=34 51-60years=43 61-70years=14	n=104 76 AN, 14 BN, 9 AN/BN 5 other (93 female, 11 male) Mean age = NR (68% 18-30 years)	SF-36	Scores did not differ according to gender of carer. However, overall carers reported significantly less mental wellbeing (lower MCS) than community norms and that of carers of other conditions. SF-36 sub-scale only scores were comparable to that of previous ED study.	Unpublished Thesis (D. Clin. Psychol.)
6. Martin et al. (2011) Spain	Cross-Sectional	246 parents, partners, or sibling/child (131 female, 115 male) Mean age = 47.9 years(SD=12.43)	n=145 64 AN, 36 BN, 45 EDNOS (143 female, 2 male) Mean age = 25.56 (SD=8.9)	SF-12	Caregivers of individual with EDs have low scores in the mental health component of QOL measure, with mothers scoring significantly lower than fathers.	Medline
7. Raenker et al. (2013) UK	Cross-sectional	252 parents, or partners (144 female, 108 male) Mothers = 53.3 years (SD=7.3) Fathers = 54.9 years (SD=8.6) Partners = 39.3years (SD=12.1)	n=178 178 AN (169 female, 9 male) Mean age = 25.8 years (SD=9.2)	WHO QoL – (short version) Social Wellbeing subscale (SWS)	Mothers and fathers were found to have similar scores for the SWS, rating the quality of life in terms of quality of social support as significantly greater than for partners. Siblings and friends were excluded from the analysis.	International Journal of Eating Disorders
8. Yu (2008) Hong Kong	RCT of a coping-focused intervention group for ED caregivers	28 parents (28 female) 14=intervention 14=control Mean age = 47.6 years (SD=8.7)	n=28 13 AN, 8 BN, 7 EDNOS (28 female) Mean age = 19.6 years (SD=5.1)	SF-12	Carers scored lower on MCS than PCS, with no significant differences between groups at baseline. Across control and intervention groups 18 carers indicated clinical scores at baseline (using a cut-off point defined by normative data from a previous Chinese population study).	Unpublished Thesis (MSocSc in Clinical Psychology)

AN = Anorexia Nervosa; BN = Bulimia Nervosa; BED = Binge Eating Disorder; EDNOS = Eating Disorder Not Otherwise Specified; NR = Not Reported; PedsQL = Pediatric Quality of Life Inventory 4.0 Generic Core Scales (Varni, Seid, & Rode, 1999); SF-36 = Short Form Health Survey (Ware & Sherbourne, 1992); SF-12 = 12-item Short Form Health Survey (MCS=Mental-Health Component Scale, PCS=Physical-Health Component Scale; Ware, Kosinski, & Keller, 1996); WHO QoL (short version) =World Health Organisation Quality of Life questionnaire (WHOQOL Group, 1998).

3.4.2 Summary of Results

A narrative synthesis of the heterogeneous group of included studies is presented under the subheadings of QoL and Type of ICs, QoL and Gender of ICs and Comparative QoL Data. The range of study designs and outcome measures utilised will be discussed throughout each heading. As QoL data by ED diagnosis of persons being cared for were not presented in any of the studies, and only one study (Linacre, 2011) presented QoL data by duration of ED, this was not considered in this review.

3.4.2.1 Quality of Life and Type of Informal Caregivers

With regards to studies with indivisible data for a combinations of family member ICs, which included mostly parents and partners, three utilised SF-36 and one SF-12 version as the outcome measure (respectively De La Rie et al., 2005, Spain; Hoyle et al., 2013, UK & Australia; Linacre, 2011, UK; Las Hayas et al., 2014, Spain). Firstly, De La Rie et al. (2005) presented SF-36 subscale means for 40 ICs in EDs: higher scores (better QoL) were found within these subscales for physical functioning and bodily pain (factors of the more physical health based summary score PCS) and lower scores (worse QoL) were for Vitality, Emotional Role Functioning and Mental health (factors of the more psychosocial based summary scale MCS). Linacre (2011) with a larger sample (n=101-102) also reported the same highest and lowest QoL subscales on the SF-36, with comparable mean scores across these two studies. In addition, a cohort study by Las Hayas et al. (2014) reported that 109 ICs of individuals with EDs had low mean QoL ratings in SF-12 MCS at T0 and 1-year later at T1 (with the mean increase differing significantly), but with no 'pathological' scores found for the PCS summary scale at any time. In contrast Hoyle et al., (2013) reported higher average SF-36 summary scores (from RCT baseline data) for ICs of people with EDs than reported by other studies with ICs. However, it is difficult to integrate these findings as it was noted that only

one score was presented in the Hoyle et al. paper and it has been suggested this is inappropriate as MCS and PCS are discrete concepts, therefore it may have skewed these data.

Three studies either focused exclusively on or allowed for individual consideration of *parent* or *partner* IC data (Martin et al., 2011, Spain; Raenker et al., 2013, UK; Yu, 2008, China). Yu (2008) found from baseline data from a RCT collected pre-intervention that the ICs scored lower on SF-12 MCS than PCS. They also reported that 18 of the 28 ICs had QoL scores at baseline below a cut point for the MCS taken from a Chinese population study. However, this parent-only study did not involve any fathers at all and was based on a small, Hong Kong specific sample limiting its generalizability. In contrast, Martin et al. (2011) utilised a cross-sectional study with 246 ICs; of these, comparison of parents (n=183) and partners (n=34) was considered. They also employed the SF-12 as an outcome measure and found similar results to Yu (2011) with comparable mean ages between samples, that MCS summary scores were lower for parents (mothers and fathers) than PCS summary scores, with all MCS scores below 50 which was reported as indicating negative perceptions of QoL. It was also reported that mothers' QoL scores were significantly poorer than fathers' in the MCS, and in the PCS mothers scored significantly worse than partners.

Another study measured ICs' QoL from an interpersonal perspective utilising the WHOQoL short-version Social Wellbeing Subscale when considering ICs in combination (Raenker et al., 2013; UK). In this cross-sectional study of the largest number of ICs across all 8 studies (n=252), they found that maternal ICs had similar scores to paternal ICs, but both rated perceptions of quality of social support as greater than partner ICs. However, this study was limited to the inclusion of care receivers with diagnoses of AN only in inpatient settings; partner ICs may have transitioned from living with to not living with the partner they care for, perhaps negatively impacting on this interpersonal domain, but also parents

may be included in therapy more increasing their sense of support. It was also reported that data were collected 1-month prior to admission which may have been a particularly challenging time and influenced ratings.

Finally, one study focused exclusively on *sibling* IC data as part of a qualitative study (Areemit et al., 2010, Canada). They found 20 siblings had PedsQL QoL averages which did not score below cut offs for impaired QoL (taken from data presented in USA 2006 study of school population children of similar ages) for all domains and summary scores. However, taking into consideration the small sample size and lack of statistical analysis, the raw mean data suggested the Psychosocial Summary QoL appeared lower than the Physical Health Summary. Emotional Functioning scores were lower than Social and School functioning scores. Six *female* siblings did report QoL scores indicative of impaired QoL, with the majority being in the Emotional Functioning domain, but whether these siblings were from gender concordant or discordant sibling pairs was not reported.

3.4.2.2 Quality of Life and Gender of Informal Caregivers

Martin et al. (2011) employed a cross-sectional design with one of the largest numbers of ICs (246 ICs; parent, partner, or sibling/child; 131 female and 115 male=53.3% female) of individuals with diagnoses of AN, BN or EDNOS, recruited via an out-patient department in Spain. They reported a significant difference between female and male ICs' mean SF-12 MCS summary scores (lower QoL scores for females), but no significant difference for the PCS summary scores. Linacre (2011) also carried out a study with a cross-sectional design but in the UK, with a smaller sample of ICs (101 ICs; parent, partner, sibling, or friend; 73 female and 28 male=72.3% female), of people with a diagnosis of AN, or BN, or AN and BN, or Other. No significant difference was found between any SF-36 mean subscale or summary scores between genders, except for the Emotional Role subscale with females

scoring lower than males just reaching significance at $p=0.05$. Although utilising the same study design, different versions of the SF outcome measure were used and the sample were from different countries with possibly different cultural caregiving and emotional disclosure expectations between females and males possibly influencing differential QoL ratings between genders. Linacre (2011) speculated that males recruited from IC support groups in their study may be better adjusted than male ICs in who do not attend support groups, impacting on the lack of gender differences found.

3.4.2.3 Studies with Comparative Quality of Life Data

Three studies, with similar types of ICs (all included parents, partners and siblings), compared their findings with normative population data. De La Rie et al. (2005) compared QoL SF-36 mean subscale scores of 40 ICs of family members of people with EDs, with those of a Dutch normative reference group published in a well cited 1998 study ($n=1742$). ICs of people with EDs reported significantly lower QoL scores for 4 of 8 subscales (which were part of the MCS summary scale), with the largest effect size for Mental Health and smallest for Social Functioning. Subscales from the PCS summary scale (Physical Role Functioning and General Health Perception), showed no significant differences between the study sample and normative data. Despite the study and normative sample being relatively well matched for age and educational status, the percentage of females in the samples differed (62.5% vs 44% in the reference group), representing a potential source of bias in findings as the analysis did not appear to be adjusted for gender.

Linacre (2011), also employing the SF-36, compared ICs of people with EDs ($n=101/102$) recruited in the UK with community norms ($n=2474$), and similarly found lower ratings on SF-36 subscales for the study sample. However, Linacre reported significant differences for more subscales (7 of 8), with physical functioning being the only exception. In

addition, although with SF-12 *summary scale* scores (MCS and PCS), Las Hayas et al. (2014) in a 2-year follow up cohort study compared scores of ICs of people with EDs at baseline, 1-year and 2-year with normative scores reported in a 2008 study with a Spanish population of a similar age. The ICs scores were significantly lower than the normative scores for all time points for the MCS only. The particular subscales where ICs were found to have lower scores than a normative population in De La Rie et al.'s (2005) study were subscales which also form part of the MCS rather than PCS, therefore these Las Hayas et al. (2014) findings are consistent with the earlier Dutch study.

In addition to demonstrating that ICs of people with EDs have lower QoL ratings on the SF-36 than a normative sample, Linacre (2011) compared ICs in the context of EDs (as a whole group, n=101) with ICs of people with dementia, brain injury (BI) and EDs. However, as dementia IC data could only be compared by gender, the focus here is on ABI and ED. It was reported that ICs of people with ED reported significantly worse Bodily Pain, General Health, Vitality, Social Functioning and Mental Health than closely matched ICs of people with BI. When ICs in EDs were contrasted with another sample of ICs in EDs with similar characteristics (De La Rie et al., 2005) their results were comparable, with only Vitality (i.e. perceived fatigue and energy levels) and Bodily Pain subscales being reported as significantly worse in Linacre's study. However, Linacre (2010) had reported whether ICs had a psychiatric diagnosis (13% of sample) whereas De La Rie and colleagues did not, therefore the ICs could have had pre-existing differences which may potentially confound their perceptions of pain and energy levels.

3.4.3 Appraisal of Included Studies

Table 3.2 provides an overview of conformity to the 22 recommendations from the STROBE guidance statement within the 8 included papers. This does not provide a comparative

measure across studies as the statement guidance is not applied with hierarchical ratings and this would assume the criteria were equally weighted, although it does provide an overview of what was and was not explicitly reported for readers to consider within each of the included studies. The items most often unreported were ‘Study Size’ (item 10; no study explicitly reported reasons for or deliberation of sample size as exemplified in STROBE elaboration paper, Vandembroucke et al., 2007), and ‘Main Results’ (item 16; the majority of studies did not report adjusted findings or outline confounder-adjustments).

Table 3.2 Appraisal of STROBE recommendations for included studies

Items (Y/N)	1.Areemit et al. (2010)	2.De La Rie et al. (2005)	3.Hoyle et al. (2013)	4.Las Hayas et al. (2014)	5.Linacre (2011)	6.Martin et al. (2011)	7.Raenker et al. (2013)	8.Yu (2008)
1. (Title & Abstract	Y	Y	Y	Y	Y	Y	Y	Y
2. Rationale	Y	Y	Y	Y	Y	Y	Y	Y
3. Objectives	Y	Y	Y	Y	Y	Y	Y	Y
4. Study Design	Y	N	Y	Y	Y	Y	Y	Y
5. Setting	Y	Y	Y	Y	Y	Y	Y	Y
6. Participants (selection)	Y	N	Y	Y	Y	Y	Y	Y
7. Variables	N	N	N	Y	Y	Y	Y	N
8. Measurement (e.g. validity / reliability)	N	N	N	N	Y	N	Y	Y
9. Bias	Y	Y	Y	Y	Y	Y	Y	Y
10. Study size (rationale)	N	N	N	N	N	N	N	N
11. Quantitative Variables	Y(descriptive only)	Y	N	Y	Y	Y	Y	N
12. Statistical methods	N/A	N	N	Y	Y	Y	Y	Y
13. Participants	Y	N	Y	Y	Y	Y	N	Y

Items Cont. (Y/N)	1.Areemit et al. (2010)	2.De La Rie et al. (2005)	3.Hoyle et al. (2013)	4.Las Hayas et al. (2014)	5.Linacre (2011)	6.Martin et al. (2011)	7.Raenker et al. (2013)	8.Yu (2008)
14. Descriptive data	Y	N	N	Y	Y	Y	Y	Y
15. Outcome data	Y	Y	Y	Y	Y	Y	Y	Y
16. Results (confounder adjustments)	N/A	N	N	N	N	N	N	N
17. Other analyses	N/A	N/A	N/A	Y	Y	Y	Y	Y
18. Key results	Y	Y	Y	Y	Y	Y	Y	Y
19. Limitations	Y	Y	Y	Y	Y	Y	Y	Y
20. Interpretation	Y	Y	Y	Y	Y	Y	Y	Y
21. Generalizability	Y	N	N	Y	Y	Y	Y	Y
22. Funding	Y	N	Y	Y	N/A (stated part of a degree)	Y	Y	N/A (stated part of a degree)

3.5. Discussion

3.5.1 Summary of Findings

This review identified eight studies which quantitatively explored QoL in ICs of individuals with EDs. It comprised a wide range of sample sizes, settings and study designs, as well as differing statistical methods and comparisons of variables, resulting in difficulties drawing direct contrasts and generalising findings across settings and IC characteristics. However, findings collectively indicated that ICs of people with EDs have low (poor) QoL ratings for mental health, emotional and social components of QoL rather than physical health components of QoL. Four studies (De La Rie et al., 2005; Las Hayas et al., 2014; Linacre, 2011; Yu, 2008) all demonstrated that ICs' ratings of QoL were lower for MCS subscales than PCS subscales. The MCS relates to areas of life including psychological distress, social functioning, and vitality/energy levels (Ware et al., 1996). Social isolation and depletion of coping resource, which could also increase distress and reduce vitality, have been reported previously in qualitative studies of ICs in EDs contexts (Hillege, Beale, & McMaster, 2006). Additionally, mental health problems and associated fear of stigma have been reported to have a negative impact on social functioning, providing some possible explanations of why MCS scores may be lower in ICs of ED clients (Perlick et al., 2001).

Consistent with the above studies, but with the advantage of having one of the largest samples of ICs across the 8 papers representing a wider range of ICs, Martin et al. (2011; the 6th study to use the SF-12/36 outcome measure) also found lower MCS QoL scores than PCS for ICs. The authors suggested this pattern fitted with the more emotional type of role in caring for someone with an EDs (dealing with more psychological distress, and emotionally charged situation e.g. mealtimes etc.) in contrast to the more physical caring role for someone who may need more assistance with daily care as in dementia. A review of caregivers in dementia outlined poor outcomes for caregivers' *physical* health (Etters et al., 2008)

consistent with the suggestion regarding role type. Overall, although only tentative interpretations can be made from this review, psychological aspects of QoL appear to be low in ICs of people with EDs, and present as lower than physical health aspects of QoL.

Findings from those studies with comparison data were also consistent with the suggestion that psychological aspects of QoL are low in ICs of people with EDs. Three studies (De La Rie et al., 2005; Las Hayas et al., 2014; Linacre, 2011) used normative reference group data from previous studies in their respective countries, all three reporting poorer MCS scores than the normative reference group scores. Linacre (2011) also compared scores with data from ICs of brain injury patients, demonstrating that ED ICs scored significantly lower on 3 of 4 mental health subscales for QoL but also significantly worse for 2 of 4 physical health subscales for QoL. However, Linacre (2011) had a slightly higher modal age of IC of individuals with EDs, possibly reducing physical health scores.

The review attempted to explore gender differences in ICs of people with ED. Previous research has suggested female ICs may experience more distress (anxiety) and more ‘overload’ (carer strain) than male ICs, possibly as they are found to be more emotionally involved in caring (Kyriacou, Treasure, & Schmidt, 2008; Whitney et al., 2005). Martin et al. (2010) and Linacre (2011) reported differing results regarding gender differences in QoL ratings for ICs of people with EDs, but gender differences could not be tested in any of the other studies in the review. Whitney et al. (2007) reported females were more likely taking a supervisory role with ED family members than males, which may suggest increased burden and decreased QoL. However the level of responsibility to take on that role may be influenced by factors such as family constellation, or active involvement in family based therapies, gender different coping styles etc., suggesting more research is required, taking into account various confounding variables.

Finally, sibling ICs included within the studies in this review appeared to receive little distinct attention. Only one study exclusively focused on siblings' data (Areemit et al., 2010). While this study did not find mean QoL scores to be below population cut offs, some female siblings were reporting ratings representative of being at risk of impaired QoL, particularly for emotional functioning subscales. This study had a very small sample and preliminary findings would suggest further research would be advantageous with much larger sample sizes to assist with replication and generalizability of findings.

3.5.2 Strengths and Limitations of the Papers

All the studies in this review utilised a standardised outcome instrument to measure QoL: carer specific measures are being developed but are reported as requiring more extensive psychometric testing before being reliably used which would explain the use of generic measures (Harvey et al., 2008). However, there was often inconsistent reporting (and lack of predetermined rationale) across studies as to which subscales or summary scales would be utilised and analysed, making comparisons even across the same measure difficult. Additionally, important participant information was not reported for some studies including i.e. type of IC (e.g. Hoyle et al., 2013), duration or severity of ED (for most), ED client gender and age (e.g. De La Rie et al., 2005), and whether IC were receiving any intervention and socioeconomic status, all of which could have influenced ICs' perceptions of their QoL. Rarely did studies describe how they would manage potential confounding variables, nor did any give predetermined explanation of sample sizes to judge statistical power, which is quite typical in observational studies (Vandenbroucke et al., 2007)

Encouragingly, some studies did report clearly the numbers of participants approached and at different stages or time points, including attrition rates and non-responders, with Areemit et al. (2010) and Las Hayas et al. (2005) for example very clearly

providing numerical information and descriptions of why this may occur. This type of information aids insight into the representativeness of the sample, including what proportion of the potential sample of ICs were prevented from taking part by the person with the ED, which could have implications for QoL scores.

Finally, a selection bias tended to be present across the included studies, with all eight studies recruiting participants from either hospital departments or support groups/websites. Although a difficult population to recruit, it may be by only regularly utilising these recruitment sources that studies are underrepresenting the perceptions of groups of ICs who are perhaps not receiving any support, may struggle to disclose their true perceptions of QoL, or do not readily identify themselves as ‘carers’ (Alderfer et al., 2010; Linacre, 2011). Linacre (2011) considered how attendees of IC support groups QoL could be influenced in either direction; with perceived improved QoL due to support from the group, or alternatively perceived lower QoL due to increased distress leading to need of a support group. The limitations would suggest that cautious conclusions should be made from this review.

3.5.2 Strengths and Limitations of the Review

The search was comprehensive and identified relevant studies from a wide range of sources (databases, journals, reference lists), including unpublished theses. While theses have not been peer-reviewed by a journal, given the post-graduate level of the research documents it is likely they will have been assessed by expert examiners. However, attempts to limit publication bias further could have been made by contacting authors of the included papers regarding any unpublished findings and by not imposing a language bias, particularly since more positive findings are reported in English language journals (Khan Kunz, Kleijnen, & Antes, 2011). Additionally, it is acknowledged that there was a lack of quality control during study screening and selection, as only one individual sifted the papers and made decisions regarding inclusion and exclusion of the papers at each stage of the review. Furthermore,

there was no second rater to independently appraise the conformity of included studies with STROBE guidance, and therefore no inter-rater reliability checks. However, a second author was involved in decisions regarding inclusion/exclusion criteria, database search terms and discussion when there was significant uncertainty regarding exclusion of a full text papers.

Additionally, the review contained a limited number of heterogeneous studies (in terms of location, design, outcome measures, ED and IC characteristics), often with small samples. This limited the ability to draw meaningful conclusions about ICs overall in EDs contexts, but also in relation to comparisons between groups since few studies employed any control or comparative matched groups. Finally, there is still a lack of clear guidance on recommended tools for use to appraise observational studies: the assessment of articles for conformity to STROBE statement guidelines in this review, although allowing for consideration of factors such as potential sources of bias, confounding variables and contextual information to support generalizability judgements, was not designed as a hierarchical rating system of methodological quality, potentially restricting the reviewer's recognition of limitations within the reviewed papers.

3.5.4 Implications for Clinical Practice

Despite the limitations of the included papers and of this review, the findings tentatively suggested that the mental wellbeing components of QoL measures seem more affected than physical wellbeing components. This indicates that psychosocial support could be useful in attempts to protect IC QoL in the face of commencing or continuing to provide informal care for a family member with an ED. In keeping with this, carers' groups, online carers' forums and UK government carer strategies have expanded recently and promote the need for local and national IC provision (DoH, 2010). Screening of perceived QoL ratings in ICs of people with EDs would be a recommended addition to clinicians' practice, to help services and

carers be more mindful of changes in ICs' perceived sense of social, emotional and physical functioning and overall QoL. This, with the direction of care becoming further community based and family members recognised as potential facilitators of change for ED clients, would be beneficial not only for ICs but also for services in the longer term, to ensure the continued caring capacity of ICs in the context of EDs (NICE, 2004; Treasure et al., 2003).

3.5.5 Future Research Needs

The current review highlighted a lack of consideration of sibling ICs in the context of EDs; Areemit et al., (2010) was the only study to exclusively focus on this group, demonstrating in this small study that over a quarter of the sibling sample self-rated QoL below the cut off reported to be indicative of impaired QoL. Qualitative and quantitative research of siblings with brothers/sisters with cancer and schizophrenia have both suggested that the burden on siblings is overlooked and underestimated, therefore more investigation needs to be commenced to understand and support prevention of further impacts on siblings, who are involved family ICs and do provide support to the patient (Alderfer et al., 2010; Nice, 2004; Schmid, Schielein, Binder, Hajak, & Spiessl, 2009). This suggests that it is important to significantly expand the extant literature base in this area by conducting studies with larger quantitative samples to increase reliability of findings which can be generalized to a wider group of sibling ICs and considering siblings' experiences of the impacts of EDs in a more detailed, qualitative manner. In addition, ED variables such as diagnosis, duration, intervention type, and participant characteristics such as socioeconomic status and ethnicity are rarely considered as moderating variables, and, as found in this review and previous reviews, are also sometimes poorly reported (Alderfer et al., 2010).

3.6. References

- Alderfer, M. A., Long, K. A., Lown, E. A., Marsland, A. L., Ostrowski, N. L., Hock, J., & Ewing, L. J. (2010). Psychosocial adjustment of siblings of children with cancer: a systematic review. *Psycho-oncology*, 19, 789-805.
- Areemit, R. S., Katzman, D. K., Pinhas, L., & Kaufman, M. E. (2010). The Experience of Siblings of Adolescents With Eating Disorders. *Journal of Adolescent Health*, 46, 569-576.
- Argimon, J. M., Limon, E., Vila, J., & Cabezas, C. (2004). Health-related quality of life in carers of patients with dementia. *Family Practice*, 21, 454–457.
- Chow, M., Morrow, A. M., Robbins, S. C. C., & Leask, J. (2013). Condition-specific quality of life questionnaires for caregivers of children with paediatric conditions: a systematic review. *Quality of Life Research*, 22, 2183-2200.
- De La Rie, S. M., Van furth, E. F., De Koning, A., Noordenbos, G, & Donker, M. C. (2005). The Quality of Life of Family Caregivers of Eating Disorder Patients. *Eating Disorders: The Journal of Treatment & Prevention*, 13, 345-351.
- Deeks, J. J., Dinnes, J., D’Amico, R., Sowden, A. J., Sakarovich, C., Song, F., et al. (2003). Evaluating non-randomised intervention studies. *Health Technology Assessment*, 7(27).
- Department of Health. (2010). *Recognised, valued and supported: next steps for the Carers Strategy*. London: HM Government.
- Engel, S. G., Adair, C. E., Las Hayas, C., & Abraham, S. (2009). Health-Related Quality of Life and Eating Disorders: A Review and Update. *International Journal of Eating Disorders*, 42, 179-187.

- Etters, L., Goodhall, D., Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of American Academy of Nurse Practitioners*, 20, 423-4287.
- Graap, H., Bleich, S., Herbst, F., Trostmann, Y., Wancata, J., & de Zwaan, M. (2008). The needs of carers of patients with anorexia and bulimia nervosa. *European Eating Disorders Review*, 16, 21-29.
- Grover, S., & Dutt, A., (2011). Perceived burden and quality of life of caregivers in obsessive-compulsive disorder. *Psychiatry and Clinical Neurosciences*, 65, 416-422.
- Harvey, K., Catty, J., Langman, A., Winfield, H., Clement, S., Burns, E., et al. (2008). A Review of Instruments Developed to Measure Outcomes for Carers of People with Mental Health Problems. *Acta Psychiatrica Scandinavica*, 117, 164-176.
- Hay, P. J., & Mond, J. (2005). How to ‘count the cost’ and measure burden? A review of health-related quality of life in people with eating disorders. *Journal of Mental Health*, 14, 539-552.
- Hayas, C. L., Padierna, J. A., Bilbao, A., Martin, J., Munoz, P., & Quintana, J. M. (2014). Eating Disorders: Predictors of change in the quality of life of caregivers. *Psychiatry Research*, 215, 718-726.
- Hillege, S., Beale, B., & McMaster, R. (2006). Impact of eating disorders on family life: individual parents’ stories. *Journal of Clinical Nursing*, 15, 1016-1022.
- Hopf, R. B. B., Le Grange, D., Moessner, M., & Bauer, S. (2013). Internet-based chat support groups for parents in family-based treatment for adolescent eating disorders: A pilot study. *European Eating Disorders Review*, 21, 215-223.
- Hoyle, D., Slater, J., Williams, C., Schmidt, U., & Wade, T. D. (2013). Evaluation of a Web-Based Skills Intervention for Carers of People with Anorexia Nervosa: A Randomized Control Trial. *International Journal of Eating Disorders*, 46, 634-638.

- Jarde, A., Losilla, J. M., & Vives, J. (2012). Methodological quality assessment tools of non-experimental studies: a systematic review. *Anales de psicología*, 28, 617-628.
- Khan, K., Kunz, R., Kleijnen, J., & Antes, G. (2011). *Systematic Reviews to Support Evidence-Based Medicine* (2nd Edn.). London: Hodder Arnold
- Kyriacou, O., Treasure, J., & Schmidt, U. (2008). Understanding How Parents Cope with Living with Someone with Anorexia Nervosa: Modelling the Factors that are Associated with Carer Distress. *International Journal of Eating Disorders*, 41, 233-242.
- Linacre, S. J. (2011). *The Wellbeing of Carers of People with Severe and Enduring Eating Disorders (SEED)*. Unpublished Manuscript, Academic Unit of Psychiatry and Behavioural Sciences, The University of Leeds, UK. Retrieved May 6, 2014, from <http://etheses.whiterose.ac.uk/2030/>
- Martín, J., Padierna, A., Aguirre, U., Quintana, J. M., Hayas, C. L., & Muñoz, P. (2011). Quality of life among caregivers of patients with eating disorders. *Quality of Life Research*, 20, 1359-1369.
- Martín, J., Padierna, A., Aguirre, U., Gonzalez, N., Muñoz, P., & Quintana, J. M.. (2013). Predictors of quality of life and caregiver burden among maternal and paternal caregivers of patients with eating disorders. *Psychiatry Research*, 210, 1107-1115.
- National Institute for Health and Clinical Excellence (NICE). (2004). *Eating Disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders*. London: National Institute for Health and Clinical Excellence. Retrieved July 16, 2011, from <http://guidance.nice.org.uk/CG9>
- Perkins, S., Winn, S., Murray, J., Murphy R., & Schimdt, U. (2004). A qualitative study of the experience of caring for a person with bulimia nervosa. Part 1: the emotional impact of caring. *International Journal of Eating Disorders*, 36, 256-268.

- Perlick, D. A., Rosenheck, R. A., Clarkin, J. F., Sirey, J. A., Salahi, J., Struening, E. L., et al. (2001). Adverse Effects of Perceived Stigma on Social Adaptation of Persons Diagnosed With Bipolar Affective Disorder. *Psychiatric Services*, 52, 1627-1632.
- Platt, S. (1985). Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales. *Psychological Medicine*, 15, 383-393.
- Raenker, S., Hibbs, R., Goddard, E., Naumann, U., Arcelus, J., Ayton, A., et al. (2013). Caregiving and Coping in Carers of People with Anorexia Nervosa Admitted for Intensive Hospital Care. *International Journal of Eating Disorders*, 46, 346-354.
- Sanderson, S., Tatt, I. D., & Higgins, J. P. (2007). Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: A systematic review and annotated bibliography. *International Journal of Epidemiology*, 36, 666-676.
- Schmid, R., Schielein, T., Binder, H., Hajak, G., & Spiessl, H. (2010). The forgotten caregivers: Siblings of schizophrenic patients. *International Journal of Psychiatry in Clinical Practice*, 13, 326-337.
- Treasure, J., Murphy, T., Szmukler, G., Todd, G., Gavan, K., & Joyce, J. (2001). The experience of caregiving for severe mental illness: a comparison between anorexia nervosa and psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 36, 343-347.
- Treasure, J., Gavan, K., Todd, G., & Schmidt, U. (2003). Changing the Environment in Eating Disorders: Working with Carers/Families to Improve Motivation and Facilitate Change. *European Eating Disorders Review*, 11, 25-37.
- Vandenbroucke, J. P., von Elm, E., Altman, D. G., Gotzsche, P. C., Mulrow, C. D., Pocock, S. J., et al. (2007). Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Explanation and Elaboration. *Epidemiology*, 18, 805-835.
- Varni, J. W., Seid M., & Rode, C. A. (1999). The PedsQL™: Measurement Model for the Pediatric Quality of Life Inventory, *Medical Care*, 37, 126-139.

- von Elm, E., Altman, D. G., Egger, M., Gotzsche, P. C., & Vandenbroucke, J. P. (2007). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies. *Bulletin of the World Health Organisation*, 85, 867-872.
- Ware Jr., J. E., Kosinski, M., & Keller, S. D. (1996). A 12-Item Short-Form Health Survey (SF-12): Construction of Scales and Preliminary Tests of Reliability and Validity. *Medical Care*, 34, 220-233.
- Ware Jr., J. E., & Sherbourne, C. D. (1992). The MOS 36-item Short-Form Health Survey (SF-36). *Medical Care*, 30, 473-483.
- Whitney, J., Murray, J., Gavan, K., Todd, G., Whitaker, W., & Treasure, J. (2005). Experience of caring for someone with anorexia nervosa: qualitative study. *The British Journal of Psychiatry*, 187, 444-449.
- Whitney, J., Haigh, R., Weinman, J., & Treasure, J. (2007). Caring for people with eating disorders: Factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders. *British Journal of Clinical Psychology*, 46, 413-428.
- WHO. (2004). *A Glossary of Terms for Community Health Care and Services for Older Persons*. Geneva: World Health Organisation.
- WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. *Psychological Medicine*, 28, 551-558.
- Winn, S., Perkins, S., Walwyn, R., Schmidt, U., Eisler, I., Treasure, J., et al. (2007). Predictors of mental health problems and negative caregiving experiences in carers of adolescents with bulimia nervosa. *International Journal of Eating Disorders*, 40, 171-178.

- Yu, P. M. W. (2008). *Stress and Coping of Parents with Daughters with Eating Disorders: An Intervention of a Coping-Focussed Intervention Group*. Unpublished Manuscript, Department of Psychology, The University of Hong Kong, China. Retrieved May 6, 2014, from <http://hub.hku.hk/bitstream/10722/55142/3/FullText.pdf>
- Zabala, M. J., Macdonald, P., & Treasure, J. (2009). Appraisal of Caregiving Burden, Expressed Emotion and Psychological Distress in Families of People with Eating Disorders: A Systematic Review. *European Eating Disorders Review*, 17, 338-349.

4. Research Article

Siblings' Experiences of having a Brother or Sister with an Eating Disorder:

A Qualitative Exploration

4.1. Abstract

Despite advancements in the knowledge base surrounding the experiences of adult carers of individuals with eating disorders, a scarcity of exploration into the sibling experience remains. Previous research has focused on Anorexia Nervosa, with predominately adult, female participants. This study, therefore explored the lived experience of eight *adolescent, male and female siblings* with a brother or sister with *Bulimia Nervosa or Eating-Disorder-Not-Otherwise-Specified*, using semi-structured interviews. An interpretative phenomenological analysis approach was utilised to analyse interview data. Three super-ordinate themes emerged: Sibling Identity, The Vulnerable Social 'Self', and Intra- and Inter-Personal Coping. Participants revealed challenging and influential development of their sibling role in relation to their affected sibling and their parent(s), with complex emotional tensions highlighted, particularly regarding sibling contemplation of their social world and acceptance of support. The findings, which provide insight into the unique experiences, feelings and various roles of these siblings, are reviewed in the context of relevant literature and emerging implications regarding sibling support are considered.

Keywords: adolescents; eating disorders; interpretative phenomenological analysis (IPA); lived experience; qualitative; siblings

4.2. Introduction

Eating disorders (EDs), including anorexia nervosa (AN), bulimia nervosa (BN) and eating disorder not otherwise specified (EDNOS), are a common clinical presentation in child and adolescent mental health services (CAMHS), with adolescence encompassing the peak age for onset, and incidence reported as 2 in 1000 for UK females aged 12-15 in 2000-2009 (Micali, Hagberg, Petersen, & Treasure, 2013; NICE, 2004; Reijonen, Pratt, Patel, & Greydanus 2003). EDs can impact significantly on family members, who are often the main carers for the individual with an ED, with diagnosis acting as a catalyst for change within the family unit's relationships and functioning (Hillegge, Beale, & McMaster, 2006; Treasure et al., 2008).

Research exploring young people with an ED and their parents' experiences appears to be increasing (e.g. Fox, Larkin, & Leung, 2011; Highet, Thompson, & King, 2005; Hillegge et al., 2006). However, a scarcity of research remains in relation to the experience of siblings and particularly adolescent siblings; despite siblings having been recognised as an important resource in the recovery and support of individuals with an ED, and specifically identified in guidance as recommended to be involved in treatment (Dimitropoulos, Klopfer, Lazar, & Schacter, 2009; Honey, Clarke, Halse, Kohn, & Madden, 2006; NICE, 2004). The overlooking of unaffected siblings in this area is disappointing as it has been suggested from mental- but also physical-health studies, that their own health and wellbeing can be greatly affected by their sibling's illness, and their relationships with the sibling just as affected as the parents' relationships (Dimitropoulos et al., 2009; Lively, Friedrich & Rubenstein, 2004). Additionally, despite considerable importance being placed on the sibling relationship and role within family-systems literature, little research, beyond the form of quantitative empirical studies and exploration of family relationships as a whole, has focused on the

sibling-sibling relationship from the perspective of the unaffected sibling in the context of EDs (Latzer, Ben-Ari, & Galimidi, 2002).

The existing *qualitative* literature attending to caring for someone with an ED, which has been predominantly from parents' viewpoints, has typically conceptualised caring for someone with an eating disorder as associated with distress and negative consequences. Hillege et al. (2006) found that parental carers identified stressors such as financial concerns, depletion of coping resource, family rifts but with competing importance placed on staying "united as a family" (p. 1019), and lack of understanding from others. However, exploration of any positive and rewarding aspects of caring for someone with an eating disorder, which had been identified in a study by Perkins, Winn, Murray, Murphy, and Schmidt (2004) as including personal development and relationship improvement, seemed lacking.

There has also been inquiry into the family experience of the time period up to and including recognition of an eating disorder, and subsequent experiences of treatment. For example, in a thematic analysis, Highet et al. (2005) reported that carers (parents, partners and friends) had difficulty accepting their suspicions of an eating disorder and experienced a range of emotions from shock, anger, blame and relief relating to diagnosis. They also revealed that these carers identified a lack of awareness of services to support carers, as well as the impact on siblings, such as increased sensitivity and detachment from the family unit. This was somewhat consistent with findings related to carers' needs and experiences of services by Winn, Perkins, Murray, Murphy, and Schmidt (2004) that identified a lack of carer support services, as well as desire for more information and practical guidance from professionals. Both studies, however, employed wide criteria for 'carer', meaning differences in experience from distinct perspectives may have unfortunately been neglected; although, positively, BN presentations and consideration of the impact on siblings had been explored

which previous studies have tended to overlook, as also acknowledged by Areemit, Katzman, Pinhas, and Kaufman (2010).

The relatively few studies that have dedicated exploration to the specific sibling impact and experience have tended to include a narrow range of participant perspectives and contexts: understandably, given the guidance surrounding homogeneous samples due to the ideographic nature of most qualitative studies (e.g. Smith, 2008); therefore leaving gaps in the current academic literature, clinicians' understanding and potentially the advancement of interventions and support for the needs of specific groups of 'unvoiced' siblings (Halvorsen, Ro, & Heyerdahl, 2013; Highet et al., 2005). Dimitropoulos et al. (2009) for instance, interviewed female *adult*-siblings who had sisters with solely AN diagnoses, whereas other researchers have interviewed *adolescent*-siblings (with ages ranging from 11-18), although again only focused on AN-presentations or exclusively female (and predominately younger) unaffected siblings' perspectives (Garley & Johnson, 1994; Latzer, et al., 2002). These studies have simultaneously displayed similarities with the parental carers' experience knowledge base and discovered dominant key themes for unaffected siblings such as: intense emotional reactions, evolving communication and relationships within the family unit, impact on the sibling's own body image and development at the vulnerable time of adolescence, as well as limitations to siblings' coping without support. Other research into the experience of having a sibling with a mental health condition has also shed light on possible positive outcomes, such as increasing compassion and sense of meaning to life, recognition of own resilience, and increasing closeness in the sibling relationship (Dimitropoulos et al., 2009; Lukens, Thorning & Lohrer, 2004).

The literature thus far has outlined the emergence of only a limited number of adolescent sibling narratives: however, adolescent *male* unaffected siblings and adolescent unaffected siblings of young people with *BN or EDNOS* are still to be the focus of research.

There are similarities between AN and BN, but each illness and its resulting impact on individuals and manifestation within a family has distinguishing features, suggesting therefore that the unique lived experience of adolescent siblings of individuals with BN or EDNOS should be discretely explored, as well as introducing the male unaffected sibling voice given societal care-giving differential expectations of males and females (Garley & Johnstone, 1994; Latzer et al., 2002; Winn et al., 2007).

One study that has focused exclusively on young (10-18 years-old) unaffected siblings of adolescents with AN or EDNOS, which also introduced a small (30%) male sample, is Areemit et al. (2010). They qualitatively explored the voice of 10 unaffected siblings using focus group interviews and quantitatively measured quality of life (QOL) after the onset of their sibling's ED. Overall the QOL scores were not indicative of impairment; however, for the siblings who did score above a cut off, with no pre-measure or comparison to a control sample it cannot be assumed that these scores related to the ED's onset. Qualitatively, key themes such as a desire to understand the ED, feelings of sacrifice and emotional duality, and pervasiveness of the ED into many aspects of unaffected siblings' lives, were identified following triangulation of different investigators' perspectives of these interview data. Although this sample was not from UK families it does not limit its theoretical transferability: although there was limited transparency regarding the interview probes utilised and no information or reflection was provided regarding the investigators who conducted the analysis, meaning their influence on the research process was difficult to consider when reviewing the findings as the reader (Yardley, 2008). Despite making advancements to the current adolescent sibling knowledge base, this 2010 study still highlighted the need for further research in this area, particularly with a focus on EDs other than AN and the inclusion of male siblings.

4.2.1 Aims of Study

The present study aimed to address the gap in the literature by qualitatively exploring in detail the lived experience of *adolescent, male and female*, unaffected siblings with a brother or sister with *BN or EDNOS*. The objective was to permit the ‘voice’ of these particular siblings to be heard through discussion of their unique experience, in terms of exploring their perspectives and opinions, and thoughts and feelings about their subjective world, discretely from the rest of their family’s experience. The findings will help develop the understanding of the sibling experience, potentially having implications for the advancement of family interventions and development of sibling support.

4.3 Method

4.3.1 Ethical Approval

Ethical approval (see Appendix D for documentation) was gained in February 2013 from an NHS Research Ethics Committee, NHS Research & Development and NHS Director of Operations management.

4.3.2 Design and Theoretical Foundation

A qualitative design, utilising a semi-structured interview data collection method was chosen to allow for in-depth, richer exploration of siblings’ lived experiences and elicitation of how they make sense of their personal, subjective experience of having a brother or sister with BN or EDNOS. Interpretative phenomenological analysis (IPA) was the qualitative methodological approach used in this study (as outlined by Smith, Flowers, & Larkin, 2009). Other qualitative methods were considered such as Grounded Theory (e.g. Charmaz, 1995), though IPA was viewed as having the most appropriate fit and relationship with the research

question, given the commitment and position on sense-making and psychological meaning of life experiences in an open, exploratory, rather than more explanatory, conceptualising, manner (Smith et al., 2009). IPA is rooted in philosophies encompassing phenomenology, hermeneutic tradition and idiography. The focus is therefore in detail on both a small number of individuals' attempts to make sense of their experiences through personal perception and meaning attributed to a specific phenomenon, coupled with the researcher's sense-making of these accounts, while iteratively reflecting on the researcher's subjectivity and preconception in this interpretative dual process (Reid, Flowers, & Larkin, 2005; Smith et al., 2009).

4.3.3 Recruitment and Participant Sample

A purposive sampling strategy was utilised between February 2013 and December 2013, with the aim of carefully recruiting a “closely defined group” (Smith, 2008, p. 56) of individuals who could offer an insight and a particular perspective into the particular experience being explored (Smith et al., 2009). For this study, this involved selecting young people aged 12-19 years, with a brother or sister (aged 12-18-years) with BN or EDNOS who was accessing CAMHS, and who had experienced living with their affected sibling at some point during the illness. In keeping with the more ideographic than nomothetic nature of IPA, sample sizes from single case studies to around 4-10 interviews has typically been advised (Smith et al., 2009; Starks & Trinidad, 2007). It is suggested the focus on quality and depth over large quantity allows for the detailed level of analysis required, as well as exploration of similarities and divergence, whilst respecting the large time-commitment expectations of qualitative analysis (Smith, 2008; Smith et al., 2009).

Research information sheets (see Appendix E) outlining the aims, nature and format of the study were distributed to CAMHS clinicians across 8 locality- and sub-teams in one NHS Scotland health-board. Information sheets were provided to the CAMHS client

(‘affected sibling’) and family by his or her clinician where appropriate. If a client agreed for their sibling (‘unaffected sibling’) to be approached about the research, a phone number was provided by the clinician to the researcher to follow-up after a minimum of 24-hours. During follow-up, any questions were answered and if verbal consent provided, a time and NHS clinic location agreed for meeting. All unaffected siblings provided their own written informed consent, however written parental assent was also obtained, promoting parental involvement as per ethical guidance (Medical Research Council, 2007; Scottish Children’s Research Network, 2012). (Template consent/assent forms can be found in Appendix F.)

A total of eight unaffected siblings (4 females, 4 males) consented to be interviewed, with a mean age of 15.0 years (range 12-19). Four were older siblings and four younger, with a mean age difference between siblings of 3.1 years (range 2-5); all had lived at home with their sibling. With respect to the eight affected siblings (7 females, 1 male), the mean age was 14.9 years (range 12-18); two had a presentation consistent with BN and six with EDNOS (see Table 4.1).

Table 4.1 Participant characteristics

<i>‘Unaffected’ Sibling Information</i>				<i>‘Affected’ Sibling Information</i>		
<i>Participant Pseudonym</i>	<i>Gender</i>	<i>Age</i>	<i>Family Status</i>	<i>Gender</i>	<i>Age</i>	<i>Diagnosis</i>
Tina	F	12	Parents together	F	17	EDNOS
Katie	F	12	Parents separated	F	14	BN
Craig	M	19	Parents separated	F	14	BN
Victoria	F	19	Parents separated	F	16	EDNOS
Edward	M	15	Parents together	F	18	EDNOS
Finn	M	15	Parents separated	F	12	EDNOS
Naomi	F	12	Parents together	F	14	EDNOS
Robert	M	16	Parents together	M	14	EDNOS

4.3.4 Interview Schedule and Procedure

An interview schedule (see Appendix G) was developed to guide, though not prescribe the semi-structured interviews; this allowed flexibility in the ordering and/or omission of particular questions and crucially freedom to pursue unique areas that individual participants divulged (Smith, 1995). The question areas were typically generated from the researcher's clinical and academic experience-base as a trainee clinical psychologist, as well as literature from studies involving IPA methodology, adult-siblings and siblings of others with various mental- and physical-health conditions. The interview schedule was discussed with a research supervisor (a practitioner psychologist working with eating disorder presentations in CAMHS) for face validity purposes (Dimitropoulos et al., 2009; Smith et al., 2009). The interview questions were typically broad and open-ended, however more specific probes and prompts were devised to aid participants, as IPA research has recognised that child and adolescent participants might require the researcher to help and guide the interview more than with adults (Smith, 2004).

The interviews were conducted by the researcher at CAMHS clinics of the participant's choice within the NHS health-board, and each participant was provided with £10 to cover travel expenses. Participants were interviewed out-with the home/school environment to take into account privacy during the interview, potentially allowing disclosure (or more free disclosure) without fear of being overheard by significant others (Duncan, Drew, Hodgson, & Sawyer, 2009). Prior to the interview, participants were asked to complete consent forms and parent/carers assent forms, within this they could also opt to receive a summary of the findings of the study on its completion.

At the start of the interview, participants were re-informed of issues contained within the research information sheets and consent forms such as confidentiality and anonymity. Methods of stopping a particular question or the interview were rehearsed to encourage their

use if required, as children might feel less able to exercise this right than adults (Kirk, 2007) (see ‘Briefing Section’ of Appendix G). The interview started with a general question (“can you tell me about who is in your family?”) that could involve drawing out family maps. This was included to develop rapport and potentially increase willingness to engage (Smith, 2004). The interviews lasted 45-60 minutes, were audio-recorded, and the researcher had a notebook to record in memo format any additional information and reflections prior to and during the interview and analysis stages. Participants were debriefed, ensuring they felt ready to leave, could ask questions, and be thanked and provided with information and helpline numbers encouraging them to talk to someone should they require this following the interview (see ‘Debriefing Section’ of Appendix G). As another ethical consideration, GPs were informed via letter (see Appendix H) of involvement in the study to ensure awareness of what this entailed, should a young person have attended their practice in need of further support following participation.

4.3.5 Transcription and Analysis

The interviews were transcribed verbatim, with identifiable information removed, by the researcher and checked against the recordings for accuracy and familiarity purposes. They were analysed using an IPA methodological approach (as outlined in Smith, 2008; Smith et al., 2009). Whilst not prescriptive due to the subjectivity of researcher’s analysis and interpretation, steps are offered (Smith, 1995). Transcripts were repeatedly re-read, with margins initially on either side to make analytic comments. During *initial noting*, the right margin was “used to annotate what is interesting or significant about what the respondent said” (Smith, 2008, p. 67), including descriptive, linguistic, and conceptual and interpretative comments (Smith, Flowers, & Larkin, 2009). Following which, the left margin was used to record *developing emerging themes*. These were at a more abstract and conceptual level

connected to the initial notes and exploratory comments, but checks were made to ensure these were still grounded in the sibling's account (Smith et al., 2009). The process of *connecting the emerging themes* explored emerging clusters and patterns of themes from a theoretical rather than chronological base, and the development of super-ordinate themes/concepts (Smith, 2008).

In keeping with the ideographic characteristic of IPA, each transcript was analysed individually in detail before moving on to another, with an attempt made to maintain an inductive stance remaining open to the development of new themes, while acknowledging the impact of preceding analyses (Reid et al., 2005). Convergence and divergence across the accounts was explored, culminating in a consolidated schematic representation of themes which were to be focus of the analytic narrative, with theme recurrence identified (see Table 4.2 in Appendix I) across accounts attempting to enhance validation of the findings (Reid et al., 2005; Smith et al., 2009). The concepts of 'hermeneutic circle' and iterative processes were central throughout the analysis, meaning the process was not linear, but rather involved repeated re-review of the ways of thinking and stages of analysis. This, for example, involved moving between initially a whole transcript to its parts as the analytic process progressed, before being re-analysed and newly influenced as a whole again. This can also be demonstrated by the dynamic interaction of moving from the original transcript towards the researcher's interpretations, but at the same time repeatedly moving back to the original transcript checking ones sense-making against a participant's words (Smith, 2008). (A sample of analysis can be found in Appendix J.)

4.3.6 Consideration of Quality and Reflexivity

The research process and analysis was not confined to one person's perspective as the researcher's supervisors were involved in discussions throughout the study and reflected their

personal perspectives and interpretations of some of the transcripts and emerging super-ordinate themes. This form of triangulation enhanced richness and credibility, exploring whether analysis made sense to others whilst still acknowledging inevitable subjectivity (Brocki & Wearden, 2006; Yardley, 2008). Additionally, samples of the analysis and schematic representation of super-ordinate theme development have been provided to increase transparency, and the findings have been grounded in excerpts to allow the reader themselves to link the data and the researcher's interpretations (Elliott, Fischer, & Rennie, 1999; Yardley, 2000).

The concept of reflexivity is also central to qualitative research, particularly when considering the role of the researcher in IPA and inevitable subjectivity. The researcher acknowledges that her personal experiences and prior and emerging assumptions would influence the research process and shape the filter through which she interpreted participants' accounts (Elliot et al., 1999). Importantly, for the reader when they try to "make sense of the researcher making sense of the participant making sense"...of their experience (Smith et al., 2009, p.41), adding another hermeneutic level, transparency and context needs to be considered (Brocki & Weardon, 2006; Yardley, 2000). The researcher was a novice qualitative researcher and did not have personal experience of having a sibling with an eating disorder. However, she is a sibling herself and has experience working clinically with young people and families. Literature had been reviewed prior to the study exploring family members' experiences of a range of mental- and physical-health conditions. Reflective practice revealed the researcher's belief that siblings were often not heard and considered in their own right, prompting interest for this study, and there was acknowledgment of her prior assumptions; for instance, that siblings would be mainly resentful of their brother/sister, readily utilise friends for support, and struggle to recognise any positives, which she realised were challenged during the research and analytic process.

4.4. Findings: The Sibling Experience

The central phenomenon was *the sibling lived experience of having a brother or sister with an eating disorder*. Three key (super-ordinate) themes emerged from the analysis of the siblings' accounts; these and the sub-themes contained within them are depicted in Figure 4.1. Whilst there were similarities across the participants' accounts and experiences, nuances were identified, both of which, illustrated by participants' excerpts, will be explored simultaneously. (*All names identified are pseudonyms; excerpts are presented in italics*)

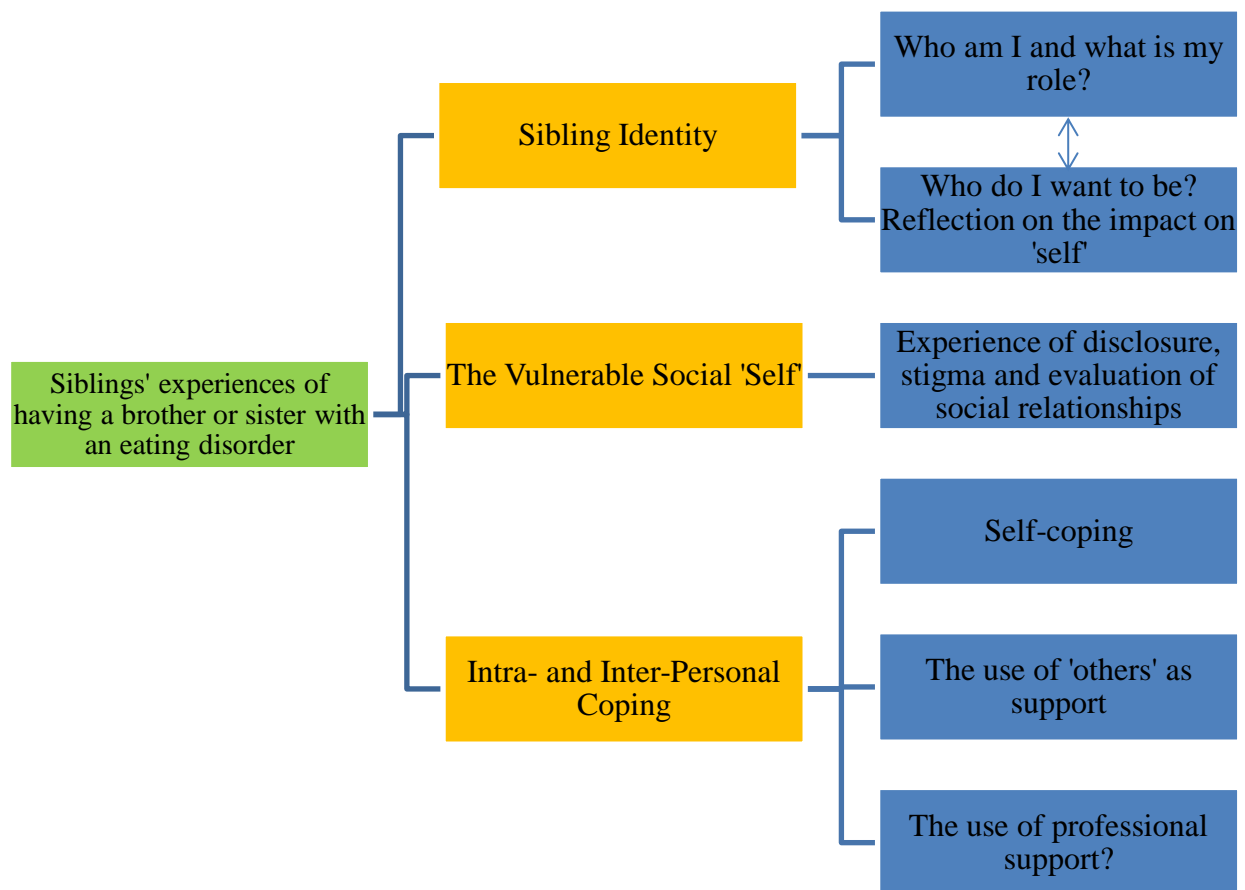


Figure 4.1 Schematic representation of key (superordinate) themes and sub-themes

4.4.1 Sibling Identity

Consideration of identity, a sense of who I am as a sibling, was interlinked with the impact their sibling's ED had on their experience of family system relationships and roles. The

sibling narratives depicted emerging and sometimes conflictual expectations of themselves, with respects to who they were and what their role was in relation to their affected sibling and also their parent(s).

Who am I and what is my role in relation to my sibling?

The sibling role in the context of the sibling-sibling relationships appeared complex. Some participants spoke about becoming confidantes to their sibling; however, this appeared more demanding than in the structure of their relationship previously and could be accompanied with personal costs. For instance:

...I didn't want {Sibling} to stop {telling me} as then it might be all in secret...But at the same time it was obviously affecting me...thinking about it 24/7, yeah...it just basically made me think I might start going downhill or stuff or feel quite low [Robert].

Siblings' reports also seemed to illustrate identification with being a 'minder' or 'spy' to their affected sibling. It seemed many instinctively took on the responsibility in their families to monitor problematic ED-related behaviours and beliefs, gathering information and evidence about the state of their sibling's wellbeing. The level of accountability siblings assigned themselves to protect their sibling from deterioration or relapse appeared excessive and more than what others may have expected or wanted them to take on. Some siblings did discuss their parents' attempts to explicitly reassure them that this role was not their responsibility. However, this *hyper*-responsibility or as one sibling experienced it a "need to focus on them 100%", continued to emerge, particularly for older siblings:

When she wasn't getting better, I thought it was time to step up and see if I could change something...I think it's my responsibility to not let her go back how she was like before...I need to make sure I do everything so it doesn't [Craig].

When the illness gets stronger...I worry over those situations, my role {as brother} has changed to watch out for this [Finn].

Adopting this ‘carer’ role could produce an uncomfortable internal conflict for many siblings. The common experience was depicted as a sense of tension between competing dual roles: that of being a supportive sibling confidante, alongside a minder, parental-type role. It could be this created confusion regarding their positioning in the family and an unfamiliar experience of pressure to align with either their parent(s) or sibling:

I thought that if I did try and take the same side as mum that I might become an enemy to {Sibling} and that I really couldn’t bear, because we were really close and that’s not something I had ever wanted to lose...but then I also worried about mum [Finn].

Sometimes I wanted to stand up for {Sibling}, sometimes I wanted to stand up for mum...I just didn’t know what to do. I wanted us to just go back to being friends...but then other times you can’t trust {Sibling}...so it’s tough for me to know how to just be her sibling [Katie].

As a result of uncertainty regarding their role in relation to their sibling following the onset of the ED, participants tended to encounter accompanying mixed emotions. A sense of guilt emerged regarding aspects of being a ‘carer/minder’, particularly when trust was broken and potential damage to their sibling relationship caused. Whilst relief and a sense of helpfulness were expressed when siblings accepted the necessity of their actions and experienced others sharing their burden:

She had to eat...it’s strange telling on my sibling...because you wouldn’t normally have to do that, you shouldn’t have to do that. {Sibling} gives me “why did you have to do that” kind of look. She’s grumpy with me, doesn’t feel good for me no, (sigh) I hope she understands why [Naomi].

It was good to say these things...my parents dealing with it took a lot of sort of strain off me...But at the same time upsetting...{Sibling} wouldn't speak to me...but telling my parents I think that sped the process {to diagnosis/support}...I could see {Sibling} just looking so confused at me...I had made things difficult as well as it changed our relationship completely (sigh) and forever [Robert].

Who am I and what is my role in relation to my parent(s)?

While participants encountered a role shift with their siblings following the onset of ED, very often developing a parent-type identity and carrying the burden of adult responsibilities, participants also assumed this adult-role with their parent(s). This appeared in the form of being like a 'second' parent or 'partner', particularly for participants in families where the parents had separated, supporting their mother/father emotionally as an equal, demonstrating great empathy and resilience for their age:

Mum acted a little more different as well, always shouting and she seemed more sad. Maybe she felt {ED} was her fault but I felt I had to keep reminding her it was not [Katie].

I knew mum was extremely angry and stressed, she had to look after {Sibling} all the time. But it was easier for mum if I was around too...mum needed me...as it would have been extremely difficult for mum to even get {sibling} to do anything if I hadn't been around [Victoria].

Adolescent siblings also took on practical duties typically assumed by parent(s) or adults. It seemed they were acutely aware of the pressure the ED was putting parents under and had the need to be useful. Often siblings described feeling helpless, especially in relation to therapy roles and ways to support their sibling's recovery, so it might be that removing these practical/everyday demands on their parent provided them some relief to or toleration of this lost, helplessness feeling:

I was doing adult jobs to take some weight off mum so I'd do washing or even sometimes ironing and stuff without being asked, she would have to deal with or make sure {Sibling} was eating...so I was having to take over the different jobs...It was my role to help in some way...[Robert].

The experiences of these types of role development were more explicitly portrayed in older siblings' accounts, but were present for all. Few showed resistance to this role and responsibility change; instead, siblings demonstrated increasing maturity but appeared often to feel a need to adopt the identity of the 'undemanding child'/'well-sibling' in a family system which they recognised was being pushed to its limits. It emerged that siblings subjugated their own needs and made sacrifices without complaint:

I had a bit of a period where {I was} more self-centred, doing stuff for me...once it got it to the point where {Sibling} was sort of really sick, I started getting more involved and stuff to support {Sibling} and mum, and well everyone really...I was kind of stressing trying to find out and sort out what was stressing them, and then try to sort it all out [Craig].

Sometimes mum would just leave it to me and I'd just have to get {Sibling} to finish eating or do whatever without a fuss...I didn't kind of voice any concerns about my feelings...I didn't want to add worry to mum about me [Victoria].

This self-sacrifice and concern for others' emotional wellbeing above their own, could also be seen with younger siblings, particularly in regard to their own eating:

I'm more aware that I need to eat a lot more and not think too much about my weight so I don't worry them {parents} too [Tina].

When {Sibling} needs a snack she will say only if you're having one...I don't want another one, but knowing it will make her eat is good...So I will just have one to make her have one [Naomi].

However, duality of emotion regarding being 'the undemanding child/sibling' did seem to gradually emerge; perhaps leading to tensions regarding what 'type' of person they wanted to be seen as within their family system. Even participants closer to adulthood seemed torn, oscillating between wanting to portray easy acceptance of 'the adult' role, while mourning loss of life as 'the child':

It was my role now to try to help mum, I enjoyed doing it because I knew that it was making her life a lot easier, but at the same time it does make me think 'why am I having to do this? why me?' My friends were out doing things, I felt I missed out [Robert].

My parents spent an awful lot of time thinking about {Sibling} really... I just kind of almost got used to doing stuff myself, ironing stuff for myself, getting myself organised, getting on with less input, but I did miss how my parents had cared for me before...[Edward].

On the whole, within this family dynamic shift, sibling-participants seemed to suppress expression of their own needs of continuing parental care and attention. Siblings play an undemanding role, prioritising others' wellbeing but often overlooking their own. As it can be difficult for others to remain mindful of unaffected children, these needs may remain unmet; however, any resentment towards the affected sibling because of this did not emerge. It could also be that as part of this undemanding role, siblings did not feel able to express this.

Who do I want to be? - Reflection on the impact on 'self'

The majority of participants alluded to positive self-developments as a result of their sibling's ED. Most spoke of influential re-evaluation of their values, particularly family, and of increasing respect for and desire to connect with family members. For example:

It proved a lot to me...how important family actually was...it also made me feel happy to know that I had a family to support us...it helped me and {Sibling}...feel a lot more open and more aware of the role I played as a sibling...I want to feel comfortable to speak to {Sibling} about anything...[Craig].

Siblings also seemed to feel they had “grown up”, strengthening their resilience and social-emotional maturation, developing an empathetic and pragmatic stance:

I'm a bit stronger too...life isn't always easy, so you need to...still try to be happy [Tina].

I have become more responsible...probably gained more sympathy for people with ED and people who have to live with people who have an ED [Victoria].

Overall I learned to be responsible, and I realised if no one ever has a bad thing happen they can never realise from it...I know it made me change [Katie].

The query, can such an influential but developmentally atypical experience be regarded without more sense of loss or cost? was raised for the researcher. Some participants did in contrast divulge that it had been a “bad” experience for them, and Katie expressed a sense of regret following the development of increased awareness:

Things changed so much it feels weird and I've had to grow up that's changed me... I'm sad as it's hard now realising we {siblings} should have been closer sooner. I regretted it and now I have started to rely on them more...I regret not spending more proper time with them [Katie].

Continuing relationship problems were outlined in some accounts, with consequence such as needing to build relationships from their foundations: “building any trust again may be a tricky

one". However, this seemed beneficial for some, with the ED being the catalyst for the resolution of previously unsatisfactory relationships or family system interaction changes:

They treat me more grown up, they felt that I've had to grow up a lot and quickly when dealing with the whole situation...thankfully we talk about things like adults now [Robert].

4.4.2 The Vulnerable Social 'Self'

The majority of siblings communicated contemplation of their social 'self' or persona during their narratives. How they would be perceived by others in their social world following disclosure of their sibling's ED, along with their evolving evaluation of social relationships during these experiences, emerged as important themes for nearly all of the participants.

Experience of disclosure, stigma and evaluation of social relationships

In a general sense, Craig described an increasing self-awareness of his multiple roles in life, but also of the value of social relationships to him:

It made me a lot more aware of who I am in terms of being a sibling, but also in terms of an individual sort of, with my friends. It also made me aware of family and social life, and how important that is in life [Craig].

It seemed for many of the siblings that a change in social self was linked to the concept of trust; specifically whether others could be trusted with the previously hidden information of their sibling's ED, somewhat like the sharing of a secret which might make them particularly vulnerable with peers:

...Obviously only close friends as I wouldn't want to tell everyone about it!...Like I only wanted to tell like two of my closest friends, because they were the ones that I had been friends with the longest and trusted the most...so it seemed fine to tell them [Robert].

Some experiences appeared to outline how trust in social relationships was not enough to encourage the uncovering of this secret, with disclosure having initially been more unintentional:

As I had to come out of school for {family therapy}...I had to explain it to people...so I explained to a couple of people at school that I trusted and I kept it to myself to those I didn't [Finn].

Robert and Finn's experiences were not isolated: others seemed to describe a reluctance to share personal information with peers and friends, with a preference to keep it within the family despite having usually told friends "their problems". This might have been as means of coping with their current experiences and struggle to combine all aspect of their lives and identity coherently, by compartmentalising their family and social self/life:

I have kept {ED} and family a fairly separate thing with most friends...We didn't speak about it much to be honest...I kept that sort of for family [Victoria].

I was still kind of escaping; I used my friends to be a different me, as didn't speak to them...about family or what was happening at home [Craig].

This lack of typical adolescent reliance on friends as confidants was also interpreted as being related to an underlying fear of stigma or prejudice, possibly given society's continuing general lack of understanding of mental health and 'invisible illness':

It's hard as you can't see it that well, not like if someone got a cold. I and people just didn't understand it at all [Robert].

Many of the participants talked about embarrassment of others knowing personal information and some even recounted previous negative interpersonal experiences, demonstrating sibling social vulnerability, fuelling insecurity and confusion regarding the use of peers as a support. Male participants spoke of a reluctance to have weakness identified and potentially used as a 'weapon' against them, potentially responding to pressures regarding societal male expectations and protecting their social persona which they had developed thus far:

*...It put me on a thought train...to be very careful in choosing who to tell because...in school I made the wrong decision about telling someone something sensitive...they took the p*ss and really made me feel awful for a long time...[Finn].*

It would have been a bit embarrassing to share this information; it sounds silly saying it but...I tend not to want to show weakness and stuff like that to people at school [Craig].

I didn't want people to know all these things about me and my family, because I think people can sometimes judge you if you've got people in your family with mental illness...I was worried about how people would react and their judgements...obviously children don't really understand...they can laugh at people and it can lead to bullying, and that would just be a disaster...[Robert].

Interestingly, Finn expressed "relief" following the discussion of mental health on the curriculum at school, seemingly encouraging disclosure due to increased understanding and social acceptability. This provided implicit permission to incorporate this aspect of his life and current identity as a sibling of an individual with an ED with what was already portrayed, metaphorically revealing the previously hidden secret.

Typically the shared experience encompassed neutral or positive outcomes from exposing and integrating this aspect of their lives into their social existence:

I know now about which friends I can trust more...after I told her, she was like always there for me so it made me feel closer to her...[Tina].

Unchanged dynamics within friendships and new awareness of sources of support and the care from friends were also recognised. However, it must be acknowledged that this was not the case for all. In the eyes of particular participants, their sibling's illness required them to include their brother/sister in their own social network, delicately attempting to combine their dual role as a sibling with that of a friend, which developmentally could have been expected to be distinct, as adolescents separate and individuate from the family system. Siblings talked about this process in terms of making social sacrifices and experiencing varied responses from friends:

I sometimes stopped going out...I'd have to say no {to friends}, so it affected that and I think they were resentful of that...Sometimes I ask my friends if {Sibling} can come with us and do things with us too, which is embarrassing and I don't know if my friends accepted that [Robert].

...I couldn't ever commit to anything with friends as I had to keep rushing back home every 5 seconds. I mean {ED} did stop me getting on with stuff with friends but thankfully didn't stop me having friendships...[Victoria].

Some disclosure experiences were portrayed less positively, with feelings of regret regarding their decisions:

I don't really know why I told her...she asks too many private things and doesn't try to understand (laughs). Sometimes {friends} bring {ED} up out of the blue and I just stand there thinking why {did I disclose} and that they don't understand...{Friend} doesn't try to guess things, if she wants to ask me a question she just will, but she's good she doesn't ask me the big things [Tina].

There was some understandable duality and a fine balance to be achieved in relation to what siblings needed from interpersonal relationships. The belief that others did not attempt to understand and just made assumptions was held by many of the participants, whilst in contradiction siblings seemed to not want others to pry or ask personal questions.

4.4.3 Intra- and Inter-Personal Coping

The emergence of a sense of tension and duality, illustrated in the preceding sections, continued when considering the siblings' coping resources. Nearly all of the participants conveyed pressure to find ways to cope independently, whilst simultaneously recognising a need for interpersonal supports, though with accompanying narratives of struggles to accept help from informal and formal sources.

Self-coping

Intra-personal coping strategies which involved building on areas of life outside of the home or ED environment were discussed by the majority of siblings. The researcher believed this served to bring a sense of 'normality' to a chaotic life with an ED present, or was used as a way to avoid the distress. Katie summarised well what the majority of male and female siblings talked about in relation to needing to escape rumination about their current reality:

It makes me feel good because then I'm thinking about other things and I'm thinking I'm enjoying myself...I like doing hobbies I like, it just makes me forgot about everything I don't like that was going on at home [Katie].

A need to escape the reality of life with an ED in the family was most emotively illustrated when siblings discussed mealtimes. Tina talked about needing to distract her attention, Katie and Victoria described it as a “warzone” escaping to the retreat of their bedrooms, and Robert succinctly outlined avoidance as a means to self-protect his emotional wellbeing, though at the cost of family functioning:

There was no let up...sometimes I would need to just get away from it all and not see it which is sad, or have meals at {Friend's} houses because I didn't want to be {at home} and experience it because I worried it would just put me in a bad mood...I tried to avoid eating with {Sibling} in the end so it was hard to have family meals like before when we'd talk and stuff [Robert].

It was noted that some of the older siblings reflected on internal thought processes and tension between rumination and acceptance. Acceptance and toleration of the situation was seen as more “helpful” in terms of coping; however, it did not seem this was an easy stance for the siblings to maintain. For example:

There's no point in debating what's fair and what's not...so there's no point of me worrying that I might end up resenting the fact that I had to deal with it...thinking about what should/could have been just wasn't helpful...I mean it still occasionally happened when I'd mull over 'oh why me why us?'...but most the time I just had to try really hard to accept it and get on with it [Victoria]

Others, particularly male participants, explained that they tried to regard themselves as not needing coping mechanisms; however, then went on to describe what seemed to amount to methods of intra-personal coping. For instance Finn and Craig reported the following:

It didn't seem like something I needed a coping strategy for...as long as I independently kept on thinking about {ED} logically it helped. I was less worried when I researched more information about it and that's the kind of the way that I got through it [Finn].

I like to ask people's opinion about it but you know at the end I like to try to sort it {problems} out in my own sort of way, so resolving these issues by myself, so I suppose I felt I had to keep this up {during sibling's ED} [Craig].

The use of 'others' as support

In the context of very close familial and social relationships some participants spoke about realising benefit from the use of others as containing emotional support, in addition to independent coping; this is illustrated through excerpts above and below from Craig:

It did help discussing it with friends...I think in the future the more opinions you get the better [Craig]

And

I would enjoy being able to speak to {family member}, because... she handled it all really well and that helped me cope [Robert].

However, it emerged from the majority of participants' accounts that there was a reluctance to accept support from their interpersonal network. Siblings appeared to hold conflicting positions between wanting support to be offered and recognising its usefulness for their coping abilities, while simultaneously not wanting to show a need for it:

I realised that was the kind of crumbling point, {parent} finally chatting to me, the breaking down the walls...it had changed me and I needed support too (long pause). But this was hard as I always thought of that as a thing that happened to other people, but I never even entertained... the concept of me needing support [Finn].

The researcher wondered whether the reticence related again to participants' need to maintain a role of 'well-sibling' within their family system, along with self-expectation to subjugate their own needs to protect others from mounting emotional demands:

{Sibling} had the problem...it was bad enough one of us having a problem...{Support} could have been helpful maybe, but I just saw myself as needing to be completely sane, I didn't want to go and seek support, I just needed to be strong for everyone in the family [Victoria].

And

Well people were good at offering {support}...I never really wanted to accept it, I would just try to brush it off and say 'oh everything's fine' because I had this thing where I didn't want to show like I was upset and stuff like that...not want to worry mum and dad more...[Robert].

Other potential barriers to the use of interpersonal support which emerged from the interviews were lack of 'space' with parents and family avoidance of speaking about the ED.

Finally, school support, although not a recurrent theme across all accounts, surfaced as important for Robert and Finn who were among some of the participants who attended the same school as their siblings. Once again there was a reluctance portrayed to actually ask for or make use of what schools could offer; however, simply having resources offered could mean they were not forgotten in the shadow of the needs of their sibling, providing a sense of recognition and containment:

There was a lot of support at school once my parents told the teachers so that helped things a lot...They would come and speak to me and ask how things were... my teachers all got an email about it then not just (sibling's) teachers...so if I was feeling down or stressed...that made teachers more understanding and more well I think it actually made them more willing to help me [Robert].

School spoke to my parents and they {offered supports}...So at last we all knew about it {ED} and I was very reassured by the fact that they {school} knew, even though I didn't use them [Finn].

Overall it seemed disclosure to school opened up the secret, providing a sense of relief from the burden of trying to manage all aspects of school with the pressure of an unwell sibling being in attendance too. Across the range of ages of participants, it remained important for others to explicitly offer and assume responsibility for initiating these supports.

The use of professional support

The subject of interpersonal support in the form of professional/formal input revealed some convergent experiences and beliefs across participants' narratives. Chiefly, there was reflection on wanting to be included, or more included, in therapy:

I would have said I would have been more happier more happy being more included {in sessions} and knowing a little bit more, but emm, I think that that's also just down to me as well...as I should have been asking more [Craig].

Most participants mentioned difficulty asking for this type of inclusion or support, but many believed it would have been useful to them for educational and emotional reasons. However, as introduced above, siblings may require adults to scaffold this access:

I'd be worried to ask mum or {clinicians} questions, could you {asked to researcher}? [Naomi].

Edward viewed professionals' role as demystifying mental health terminology and helping him come to terms with his sibling's mental health condition:

I didn't to be honest know what it {ED/sectioning} really was until somebody at {CAMHS} explained it...having only heard it to do with like psychotic murders and criminal novels...it seemed strange to apply to my sibling as they were a normal person...so they helped me with that [Edward].

Potential barriers to the uptake of formal sibling support seemed to be little awareness of available supports, a lack of explicit (and recurrent) offers from professionals, and sibling concerns regarding expectations of themselves in relation to therapy:

When {Sibling} first started treatment...the therapist asked if it was ok for me to {join them}, just for her to explain things to me...that would have been helpful I think, but that was only {offered} at the very start [Tina].

There might have been support for me or might not have been, no one really mentioned it or I suppose I didn't directly ask so I never found out...also in {family sessions} they asked questions that I didn't know how to answer, didn't know the answer to, and I felt I should [Edward].

Overall there was positive agreement among participants regarding the importance of sibling inclusion; however very few siblings mentioned being offered or having a therapeutic space solely for themselves. Robert clearly expressed how this could have been beneficial:

Talking to somebody openly, maybe asking me...how I was, how I was coping, because it would always be my parents that would go with {Sibling}!...because I definitely felt upset and at the times worried...and sometimes confused...speaking to somebody other than just {family member} would have helped me a lot...it was literally so much to take in...really mind blowing stuff [Robert].

This portrayed an unmet need for a 'safe' space to have their unique voice and story listened to and validated, separate from that of the affected sibling and parents, free from concerns of upsetting or burdening others, with 'outsider' support to process the experience of having a sibling with an ED. From participating in this study's interviews, half of the participants (mostly male) explicitly recognised this need, possibly for the first time:

It's been good thank you...it's good to get {memories} out and share my experiences [Robert].

Thank you though...a huge relief and weight off my shoulders to have the chance to speak to you about my experiences. There was so much built up inside I think and I haven't had the chance to speak about any of this before really, so thanks again [Finn].

4.5. Discussion

4.5.1 Consideration of Main Findings within Existing Literature

This study qualitatively explored a particular gap in the current knowledge base surrounding adolescent sibling experiences of having an adolescent brother or sister with an ED, specifically BN or EDNOS. The current findings suggest that Sibling Identity, The Vulnerable Social 'Self', and Intra- and Inter-Personal Coping were pertinent themes for these particular siblings. The findings reinforced the complexity of this life event and experience upon 'unaffected' siblings, bringing to light difficulty adjusting to competing sibling roles and assumed responsibilities within family systems, and social challenges during participants' attempts to manage their sibling identity alongside the social aspect of their life out with the family unit. Dual and conflictual emotions were acknowledged, particularly in the context of feeling torn within their sibling roles and in their recognition of a need for, but barriers to, interpersonal support.

In comparison with previous literature of caring for an individual with an eating disorder, the current findings displayed consistencies with adult (parent and sibling) participants' experiences of family dynamic changes, lack of awareness of support, and recognition of positive impacts of having a family member with an eating disorder (Dimitropoulous et al., 2009; Highet et al., 2005; Hillege et al., 2006). One key similarity was role tensions; Highet et al. (2005) presented findings which explored how living with an ED

in the family increased parental strain, with demands to manage new competing roles. In relation to adolescent siblings, Garley and Johnson (1994) portrayed a significant sense of responsibility towards their sibling, conflicted with an expectation to remain as an equal in the family, as a sibling and presumably not a carer/‘parent’. Siblings in the current study also seemed to experience this conflict and tension regarding newly assumed and competing roles, but spoke further of the impact, or feared impact, on the quality of their sibling-sibling relationships, which is particularly important during teenage years as this may be predictive of longer-term sibling relations (Department of Human Services, 2005; as cited in Griffiths & Sin, 2013). Being a loyal confidante, which can be a unique characteristic of a sibling relationship (Howe et al., 2001), often shifted into monitoring progress and eating, or reporting back to parents, responsibilities more in line with that of a parent figure of authority, which may disrupt the reciprocal, honest nature of the relationship and typical equal hierarchy of siblings within some family structures (Latzer et al., 2002).

Most siblings in this study described feeling this was an atypical, unwanted role with their affected siblings; however, at the same time, seemed to accept this with little resistance. It could be that this was the better of two difficult positions, as this role might have functioned to provide them a sense of more defined helpfulness when the presence of an ED was blurring expectations. Some previous literature has reported siblings explicitly being asked to take this position; but in slight contrast, adult siblings resisted this or breaking sibling-sibling trust (Dimitropoulos et al., 2009). It would be reasonable for younger aged siblings to feel the need to obey adults/parents if asked to do this, though most siblings interviewed during this exploration appeared to do this of their own accord, as it more typically reported throughout the sibling experience literature. Exploration of how families and adolescent brothers and sisters might be helped to remain in a preferred non-hierarchical sibling role, with clear responsibilities and boundaries in their relationship, does not seem to

be reported. This could possibly benefit sibling coping with the unique demands the ED places on them and the sibling relationship, which is of great importance during teenage years, but seemingly perceived to be particularly vulnerable.

One participant revealed how these types of tensions, burdens and helplessness resulted in a “breaking point” and others introduced concerns over their own emotional wellbeing, which concurs with finding from a limited range of existing studies (Areemit et al., 2010; Dimitropoulos et al., 2009), which reported an impact on siblings’ health, mood and body image. Siblings seemed often to suppress their feelings and needs, which may have been further complicated by heightened emotional states associated with adolescence, possibly as means to remain in the ‘undemanding/well’ role for their parents. This is understandable given the context of a sense of difficulty tolerating helplessness, and acute awareness of their parents’ mounting demands and stress. Not surprisingly, this has been reported in siblings’ experiences of other types of EDs and mental health problems more generally (Areemit et al., 2010; Garley & Johnson, 1994; Lukens et al., 2004).

Less explored in previous literature of adolescent siblings experiences, it was revealed in the current study that siblings also experienced a new dynamic in their child-parent relationship, becoming in some ways a ‘partner’ or ‘the 2nd parent’ practically, but also heavily emotionally supporting most often their mother. This arose particularly for the older-adolescent siblings, making it hard to comment on whether this was related to, for instance, having a sibling with an ED, participants’ age and emotional maturity being more in line with that of the adults in their family, or a pattern that predated the onset of the ED. An additional consideration was that for these older participants, most were also from families where the parents had separated and were living apart. This structural difference in the family constellation could have also significantly shaped these participants’ experiences of assuming a role of a 2nd parent. Feelings of sacrifice, anger, resentment, accompanied with a sense of

loss of childhood, have previously been brought to light and emerged in the current study, although no sense of resentment towards the sibling or parent(s) emerged in the current study as the researcher had supposed (Areemit et al. 2010; Highet et al., 2005; Lukens et al., 2004). This lack of expression may have been because they continued to hold the ‘undemanding’ stance during interviews, had concerns about the impact of family finding out, potentially a limitation of the researcher working and conducting the interviews in the service where the family accessed healthcare-providers, or did not feel comfortable to share more negative aspects on the first time meeting the researcher, despite efforts to provide a safe and validating environment. Often siblings in this study perceived this somewhat imposed maturation from role changes as a positive, personal development, sometimes contributing to improved family interactions. Positive growth following difficult life crises is not a novel concept within the human experience; factors including cognitive coping style, influenced by ability to disclosure within the context of a supportive and stable social support network have been proposed as linked to the understanding of this (Tedeschi & Calhoun, 2004), although siblings can encounter difficulties associated with these crucial social experiences.

The study revealed new insights into adolescent siblings’ challenges integrating their social and family/sibling ‘self’. Adolescence is theorised as a critical period for establishing identity, with the sibling relationship also proposed as contributing to identity development (Cicirelli 1995; as cited in Lukens et al., 2004). There is a natural strive for independence and distance from their family, with the social world and disclosure with peers taking priority (Barrera, Blumer, & Soenksen, 2011; Howe et al., 2001). Interviewees revealed that their brother or sister’s EDs could reduce the usual boundaries between their family members and their peer group, as a need was felt by siblings to monitor their sibling outside the home or improve their sibling’s social life. Issues with peer trust and careful deliberation over disclosures about their siblings’ ED, which seemed to be initially hidden as a ‘secret’

particularly in the public arena of the school environment, was a recurrent theme across accounts, more so than reported in other adolescent siblings' explorations. It may be assumed that self-disclosure would lead to increased empathy or social support, although not feeling understood or accepted by peers was a common experience for the siblings in this study and concurred with parents' experiences of a having child with an ED (e.g. Cottee-Lane, Pistrang, & Bryant-Waugh, 2004; Hillege, 2006).

The value of social support in facilitating aspects of carer wellbeing, and shaping ones processing and perception of life events can be considerable (Tedeschi & Calhoun, 2004; Winn et al., 2004). The majority of siblings, and interviewees from past studies related to having a family member with an ED, do not disagree with the importance of informal social and formal professional support; however, the experience of accepting support appeared more nuanced. Some, particularly male and older siblings, seemed to put pressure on themselves to cope independently, which can be viewed as in line with the findings outlined above regarding sibling need to be the 'undemanding/well' family member, therefore supressing feelings, or the typical adolescent development into autonomy. Divergent male and female expectations regarding the acceptability of being seen as in need for support may have been present, although further exploration would certainly be required as this was not a focus of the current study. It may also be that schools are an unexplored, underused avenue of support: a couple of siblings valued their schools being involved, allowing more disclosure of the 'secret', and one sibling talked of the helpfulness for acceptability of discussing mental health. The offer of supports, regardless of uptake, appeared appreciated.

The findings that siblings experienced a fear of judgement and stigma, which may have also acted as a barrier to adolescent siblings accepting the use of peers for disclosure and social support, expands on Areemit et al. (2010) findings. For a few, this seemed to stem from past adverse social experiences of sharing personal information, but for the majority, a

perception regarding their interpersonal network or society's poor understanding of mental health problems was held. Perceived stigma can impact on social functioning: Perlick et al. (2001) reported that concerns of 16+ year-olds regarding stigma can compromise social interaction with those out with the family, and they noted avoidant coping and secrecy surrounding mental health conditions. However, despite this fear, some siblings did receive and utilise support from social interpersonal networks following disclosure.

Finally, a clinical and service-level relevant finding from the current study was that adolescent siblings seemed to have a wish to be included, or more included, in their affected sibling's treatment or family therapy, despite recommendations for this to happen (NICE, 2004). Those who were involved found benefits from this, including educational, directive and emotional support to help manage their role and experience. This concurs with Rethink Siblings network survey that found: 1) siblings desire more information and support with coping, 2) want to hear the experiences of others, and 3) professionals reported not being in any or having infrequent contact with siblings in a family affected by mental illness (Rethink, 2011). Factors such as affected siblings' confidentiality, as well as a belief held by parents that excluding the unaffected sibling will 'protect' them, have been outlined previously as possible obstacles to sibling inclusion (Griffiths & Sin, 2013, Winn et al., 2004). There also, more specifically seemed to be a sibling 'voice' requesting professional recognition and support, or at a minimum *offers* of potential support, to talk honesty about *their* feelings and experiences. This did not necessarily appear to be suggesting therapy, but provision of a validating, containing space solely for the unaffected sibling. Some siblings alluded to professionals not always explicitly or recurrently offering support, suggesting a need for further professional responsibility to ensure this happens. Siblings' lack of awareness of what was available to them from services (e.g. NHS, community, online), potential confusion over what they needed from or expected of support, and a lack of confidence to ask for this, not

unexpected of this age of adolescents, also seemed to hinder siblings' opportunity to have a supportive space separate from their family.

4.5.2 Strengths and Limitations of the Study

The use of a qualitative methodology provided a key strength in being able to truly capture insights into the experiences of a particular group of siblings previously overlooked in the research, while contributing to meeting what siblings seemingly felt was an unmet need: time and space to share their story. Although qualitative analysis is inevitably subjective and subject to bias, independent review of some of the transcripts by the second and third authors, allowing for reflection and alternative perspectives of the analysis and emerging themes, was beneficial to this study. A limitation was not having more or all of the analysis explored in this way. Had there been scope to obtain participants understanding and feedback of the researcher's understandings and interpretations, this would have allowed for validation of the findings, adding credibility. These forms of researcher triangulation and respondent validation are routinely offered as guidance for improving the quality of qualitative research (Tong, Sainsbury, & Craig, 2007).

A strength in terms of 'rigor' came from the development of the interview schedule in conjunction with a practising CAMHS ED clinician, improving appropriateness and quality, and the sample selection was careful to be considerate of appropriateness and reasonable homogeneity (Yardley, 2008). While it is recognised that the sample size in this study was small, it is in line with recommendations surrounding the use of an IPA approach (Smith et al., 2009). A limitation is that the age range of participants was fairly heterogeneous and exposed a diverse ability of reflective and expressive functioning across siblings. However, although this study did present the findings from the group as a whole, sensitivity to nuances was explored and findings grounded in the data. It could be that tighter criteria could be

applied to define the sample of siblings; however, the pragmatics of accessing this already narrowly represented group of participants available to services could prove difficult.

As the interview data were gathered from siblings who *wanted* to take part, different findings might have emerged from individuals who were not interested in the study or were excluded from being approached by affected siblings and/or parents. Additionally, as recruitment was only from families who had involvement with CAMHS, their experiences and roles within the family may have been confounded by this, and may be different to those who could have been recruited through alternative community services. It is also possible that a bias was present during the provision of study information packs to families by clinicians already involved in the family's care: professionals may have only provided this to families with less complex family dynamics or at particular stages of treatment.

4.5.3 Implications and Further Research

The current study illustrated an unmet need in terms of formal support for adolescent siblings. The findings demonstrated professionals did not always very explicitly, or recurrently, explore or offer avenues of support for unaffected siblings. It seemed this could have helped the processing of experiences of having a brother or sister with an ED and potential facilitated sibling role definition and emotional wellbeing; therefore clearer guidance on how families and professionals actively involve and support siblings is needed. Audits within services are also recommended to explore how often siblings are included in interventions such as family based therapies, in line with treatment recommendations. As young people can understandably be anxious of directly asking for support, adults, school, and particularly professionals working with families affected by EDs need to ensure they are taking responsibility for initiating this. Additionally, consideration of existing or new service provision is required to ensure siblings, who are greatly impacted by their brother or sister's

ED, are provided with a space for their own needs to be met. This could take the form of low-level 1:1 psycho-education: rather than formal therapy sessions given emerging stigma concerns and need to be the ‘well’ sibling: providing siblings with time to talk about their experiences, access information, develop coping skills and have feelings normalised. Alternatively, group support has previously been recognised as helpful as a means to give siblings the opportunities to share with and hear from other siblings in a more accepting environment, but few local or regional sibling-specific groups/online forums seem to operate.

Future research to investigate in more detail what siblings require from services and professionals is recommended to assist with the development of sibling support. Any provision of this should also be evaluated: given services such as the NHS are already stretched caring for ‘the primary client’, added value would need to be demonstrated. Further exploration of the male sibling experience is still required to represent their distinct voice in the literature, and follow-up studies of siblings’ experiences of any longer-term positive or negative intra- or inter-personal impacts post affected-sibling recovery and professional involvement may provide interesting insights. Finally, the typography of ‘family’ in which siblings can be part also includes single-parent families, step families, and multi-generations living together. Their unique lived experiences require more focused explorations as role developments, interpersonal support and impacts on unaffected siblings may vary.

4.5.4 Conclusion

The study has taken a step towards addressing relatively recent concerns regarding the lack of attention and qualitative research into the experience of specific groups of siblings of individual with EDs (Areemit et al., 2010; Halvorsen et al., 2013). Providing siblings with a ‘voice’ separate from the rest of their families, has both enriched the extant knowledge base and provided new insights into the complex adolescent sibling experience of having a brother

or sister with BN or EDNOS. The findings and implications may increase awareness and help others remain mindful of the needs of siblings when supporting children and adolescents with EDs. Narratives of the experiences of specifically male siblings remains overlooked.

4.6 References

- Areemit, R. S., Katzman, D. K., Pinhas, L., & Kaufman, M. E. (2010). The Experience of Siblings of Adolescents With Eating Disorders. *Journal of Adolescent Health, 46*, 569-576.
- Barrera, A. M., Blumer, M. L. C., & Soenksen, S. H. (2011). Revisiting Adolescent Separation-Individuation in the Contexts of Enmeshment and Allocentrism. *The New School Psychology Bulletin, 8*, 70-82.
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health research. *Psychology & Health, 21*, 87-108
- Charmaz, K. (1995). Grounded theory. In J. A. Smith, R. Harre, & L.V. Langenhove (Eds.), *Rethinking Methods in Psychology*. (pp. 27-49). London: Sage.
- Cottee-Lane, D., Pistrang, N., & Bryant-Waugh, R. (2004). Childhood onset anorexia nervosa: The experience of parents. *European Eating Disorders Review, 12*, 169–177.
- Dimitropoulos, G., Klopfer, K., Lazar, L., & Schacter, R. (2009). Caring for a Sibling with Anorexia Nervosa: A Qualitative Study. *European Eating Disorders Review, 17*, 350-365.

- Duncan, R. E., Drew, S. E., Hodgson, J., & Sawyer, S. M. (2009). Is mum going to overhear this? Methodological and ethical challenges in qualitative health research with young people. *Social Science & Medicine*, 69, 1691-1699.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.
- Fox, A. P., Larkin, M., & Leung, N. (2011). The Personal Meaning of Eating Disorder Symptoms. *Journal of Health Psychology*, 16, 116-125.
- Garley, D., & Johnson, B. (1994). Siblings and eating disorders: A phenomenological perspective. *Journal of Psychiatric and Mental Health Nursing*, 1, 157-164.
- Griffiths, C., & Sin, J. (2013). Rethinking siblings and mental illness. *The Psychologist*, 26 (11), 808-810.
- Halvorsen, I., Ro, O., & Heyerdahl, S. (2013). Nine-Year Follow-up of girls with Anorexia Nervosa and their Siblings: Retrospective Perceptions of Parental Bonding and the Influence of Illness on their Everyday Life. *European Eating Disorder Review*, 21, 20-27.
- Hight, N., Thompson, M., & King, R. M. (2005). The experience of Living with a Person with an Eating Disorder: The Impact on the Carers. *Eating Disorders*, 13, 327-344.
- Hillege, S., Beale, B., & McMaster, R. (2006). Impact of eating disorders on family life: individual parents' stories. *Journal of Clinical Nursing*, 15, 1016-1022.
- Honey, A., Clarke, S., Halse, C., Kohn, M., & Madden, S. (2006). The Influence of Siblings on the Experience of Anorexia Nervosa for Adolescent Girls. *European Eating Disorder Review*, 14, 315-322.

- Howe, N., Aquan-Assee, J., Bukowski, W. M., Lehouz, P. M., & Rinaldi, C. M. (2001). Siblings as Confidants: Emotional Understanding, Relationship Warmth, and Sibling Self-Disclosure. *Social Development, 10*, 439-454.
- Kirk, S. (2007). Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *International Journal of Nursing Studies, 44*, 1250-1260.
- Latzer, Y., Ben-Ari, A., & Galimidi, N. (2002). Anorexia nervosa and the family: Effects on younger sisters to anorexia nervosa patients. *International Journal of Adolescent Medicine and Health, 14*, 275-281.
- Lively, S., Friedrich, R. M., & Rubenstein, L. (2004). The effect of disturbing illness behaviours on siblings of persons with schizophrenia. *Journal of the American Psychiatric Nurse Association, 10*, 222-232.
- Lukens, E. P., Thorning, H., & Lohrer, S. (2004). Sibling Perspectives on Severe Mental Illness: Reflections on Self and Family. *American Journal of Orthopsychiatry, 74*, 489-501.
- Medical Research Council. (2007). *MRC Ethics Guide: Medical research involving children*. Retrieved November 13, 2012, from <http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC002430>
- Micali, N., Hagberg, K. W., Petersen, I., & Treasure, J. L. (2013). The incidence of eating disorders in the UK in 2000–2009: findings from the General Practice Research Database. *BMJ Open, 3*, [e002646]doi: 10.1136/bmjopen-2013-002646.

- National Institute for Health and Clinical Excellence (NICE). (2004). *Eating Disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders*. London: National Institute for Health and Clinical Excellence. Retrieved July 16, 2011, from <http://guidance.nice.org.uk/CG9>
- Perkins, S., Winn, S., Murray, J., Murphy R., & Schimdt, U. (2004). A qualitative study of the experience of caring for a person with bulimia nervosa. Part 1: the emotional impact of caring. *International Journal of Eating Disorders*, 36, 256-268.
- Perlick, D. A., Rosenheck, R. A., Clarkin, J. F., Sirey, J. A., Salahi, J., Struening, E. L., et al. (2001). Adverse Effects of Perceived Stigma on Social Adaptation of Persons Diagnosed With Bipolar Affective Disorder. *Psychiatric Services*, 52, 1627-1632.
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18 (1), 20-23.
- Reijonen, J. H., Pratt, H. D., Patel, D. R., & Greydanus, D. E. (2003). Eating Disorders in the Adolescent Population: An Overview. *Journal of Adolescent Research*, 18, 209-222.
- Rethink. (2011). *Rethink Brothers and sisters: Introducing Rethink Sibs: a space for siblings affected by mental illness*. Retrieved April 6, 2013, from <http://www.rethink.org/media/465838/Siblings%20Network%20report%202011.pdf>
- Scottish Children's Research Network. (2012). *ScotCRN Guidance: Obtaining informed consent for clinical research in children and young people under 16 in Scotland*. 7.08.12 (Version 1). Retrieved November 13, 2012, from <http://www.scotcrn.org/informed-consent/>

- Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In J. A. Smith, R. Harre, & L. Van Langenhove (Eds.), *Rethinking methods in psychology* (pp. 9–26). London: Sage.
- Smith, J. A. (2004). Reflecting on the development of IPA and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1*, 39-54.
- Smith, J. A. (Ed.). (2008). *Qualitative Psychology: A practical guide to research methods* (2nd ed.). London: Sage.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.
- Starks, H., & Trinidad, S. B. (2007). Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory. *Qualitative Health Research, 17*, 1372-1380.
- Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic Growth: Conceptual Foundations and Empirical Evidence. *Psychological Inquiry, 15*, 1-18.
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*, 349-357.
- Treasure, J., Sepulveda, A. R., MacDonald, P., Whitaker, W., Lopez, C., Zabala, M., et al. (2008). The Assessment of the Family of People with Eating Disorders. *European Eating Disorders Review, 16*, 247-255.

- Winn, S., Perkins, S., Murray, J., Murphy R., & Schimdt, U. (2004). A Qualitative Study of the Experience of Caring for a Person with Bulimia Nervosa. Part 2: Carers' Needs and Experiences of Services and Other Support. *International Journal of Eating Disorders*, 36, 269-279.
- Winn, S., Perkins, S., Walwyn, R., Schmidt, U., Eisler, I., Treasure, J., et al. (2007). Predictors of Mental Health Problems and Negative Caregiving Experiences in Carers of Adolescents with Bulimia Nervosa. *International Journal of Eating Disorders*, 40, 171-178.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15, 215-228.
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Methods* (2nd ed.) (pp. 234-251). London: Sage.

5. Thesis Reference List

- Alderfer, M.A., Long, K.A., Lown, E.A., Marsland, A.L., Ostrowski, N.L., Hock, J. & Ewing, L.J. (2010). Psychosocial adjustment of siblings of children with cancer: a systematic review. *Psycho-oncology*, 19, 789-805.
- Areemit, R.S., Katzman, D.K., Pinhas, L. & Kaufman, M.E. (2010). The Experience of Siblings of Adolescents With Eating Disorders. *Journal of Adolescent Health*, 46, 569-576.
- Argimon, J.M., Limon, E., Vila, J. & Cabezas, C. (2004). Health-related quality of life in carers of patients with dementia. *Family Practice*, 21, 454–457.
- Barrera, A.M., Blumer, M.L.C. & Soenksen, S.H. (2011). Revisiting Adolescent Separation-Individuation in the Contexts of Enmeshment and Allocentrism. *The New School Psychology Bulletin*, 8, 70-82.
- Brocki, J.M. & Wearden, A.J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health research. *Psychology & Health*, 21, 87-108
- Charmaz, K. (1995). Grounded theory. In J.A. Smith, R. Harre & L.V. Langenhove (Eds.), *Rethinking Methods in Psychology*. (pp.27-49). London: Sage.
- Chow, M., Morrow, A.M., Robbins, S.C.C. & Leask, J. (2013). Condition-specific quality of life questionnaires for caregivers of children with paediatric conditions: a systematic review. *Quality of Life Research*, 22, 2183-2200.
- Cottee-Lane, D., Pistrang, N. & Bryant-Waugh, R. (2004). Childhood onset anorexia nervosa: The experience of parents. *European Eating Disorders Review*, 12, 169–177.

- De La Rie, S.M., Van furth, E.F., De Koning, A., Noordenbos, G. & Donker, M.C. (2005). The Quality of Life of Family Caregivers of Eating Disorder Patients. *Eating Disorders: The Journal of Treatment & Prevention*, 13, 345-351.
- Deeks, J.J., Dinnes, J., D'Amico, R., Sowden, A.J., Sakarovitch, C., Song, F., *et al.* (2003). Evaluating non-randomised intervention studies. *Health Technology Assessment*, 7(27).
- Department of Health. (2010). *Recognised, valued and supported: next steps for the Carers Strategy*. London: HM Government.
- Dimitropoulos, G., Klopfer, K., Lazar, L. & Schacter, R. (2009). Caring for a Sibling with Anorexia Nervosa: A Qualitative Study. *European Eating Disorders Review*, 17, 350-365.
- Duncan, R.E., Drew, S.E., Hodgson, J. & Sawyer, S.M. (2009). Is mum going to overhear this? Methodological and ethical challenges in qualitative health research with young people. *Social Science & Medicine*, 69, 1691-1699.
- Elliott, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.
- Engel, S.G., Adair, C.E., Las Hayas, C. & Abraham, S. (2009). Health-Related Quality of Life and Eating Disorders: A Review and Update. *International Journal of Eating Disorders*, 42, 179-187.
- Etters, L., Goodhall, D. & Harrison, B.E. (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of American Academy of Nurse Practitioners*, 20, 423-4287.

- Fox, A.P., Larkin, M. & Leung, N. (2011). The Personal Meaning of Eating Disorder Symptoms. *Journal of Health Psychology*, 16, 116-125.
- Garley, D. & Johnson, B. (1994). Siblings and eating disorders: A phenomenological perspective. *Journal of Psychiatric and Mental Health Nursing*, 1, 157-164.
- Graap, H., Bleich, S., Herbst, F., Trostmann, Y., Wancata, J. & de Zwaan, M. (2008). The needs of carers of patients with anorexia and bulimia nervosa. *European Eating Disorders Review*, 16, 21-29.
- Griffiths, C. & Sin, J. (2013). Rethinking siblings and mental illness. *The Psychologist*, 26 (11), 808-810.
- Grover, S. & Dutt, A., (2011). Perceived burden and quality of life of caregivers in obsessive-compulsive disorder. *Psychiatry and Clinical Neurosciences*, 65, 416-422.
- Halvorsen, I., Ro, O. & Heyerdahl, S. (2013). Nine-Year Follow-up of girls with Anorexia Nervosa and their Siblings: Retrospective Perceptions of Parental Bonding and the Influence of Illness on their Everyday Life. *European Eating Disorder Review*, 21, 20-27.
- Harvey, K., Catty, J., Langman, A., Winfield, H., Clement, S., Burns, E., *et al.* (2008). A Review of Instruments Developed to Measure Outcomes for Carers of People with Mental Health Problems. *Acta Psychiatrica Scandinavica*, 117, 164-176.
- Hay, P.J. & Mond, J. (2005). How to 'count the cost' and measure burden? A review of health-related quality of life in people with eating disorders. *Journal of Mental Health*, 14, 539-552.

- Hayas, C.L., Padierna, J.A., Bilbao, A., Martin, J., Munoz, P. & Quintana, J.M. (2014). Eating Disorders: Predictors of change in the quality of life of caregivers. *Psychiatry Research*, 215, 718-726.
- Highet, N., Thompson, M. & King, R.M. (2005). The experience of Living with a Person with an Eating Disorder: The Impact on the Carers. *Eating Disorders*, 13, 327-344.
- Hillegge, S., Beale, B. & McMaster, R. (2006). Impact of eating disorders on family life: individual parents' stories. *Journal of Clinical Nursing*, 15, 1016-1022.
- Honey, A., Clarke, S., Halse, C., Kohn, M. & Madden, S. (2006). The Influence of Siblings on the Experience of Anorexia Nervosa for Adolescent Girls. *European Eating Disorder Review*, 14, 315-322.
- Hopf, R.B.B., Le Grange, D., Moessner, M. & Bauer, S. (2013). Internet-based chat support groups for parents in family-based treatment for adolescent eating disorders: A pilot study. *European Eating Disorders Review*, 21, 215-223.
- Howe, N., Aquan-Assee, J., Bukowski, W.M., Lehouz, P.M. & Rinaldi, C.M. (2001). Siblings as Confidants: Emotional Understanding, Relationship Warmth, and Sibling Self-Disclosure. *Social Development*, 10, 439-454.
- Hoyle, D., Slater, J., Williams, C., Schmidt, U. & Wade, T.D. (2013). Evaluation of a Web-Based Skills Intervention for Carers of People with Anorexia Nervosa: A Randomized Control Trial. *International Journal of Eating Disorders*, 46, 634-638.
- Jarde, A., Losilla, J.M. & Vives, J. (2012). Methodological quality assessment tools of non-experimental studies: a systematic review. *Anales de psicología*, 28, 617-628.

- Khan, K., Kunz, R., Kleijnen, J. & Antes, G. (2011). *Systematic Reviews to Support Evidence-Based Medicine* (2nd Edn.). London: Hodder Arnold
- Kirk, S. (2007). Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *International Journal of Nursing Studies*, 44, 1250-1260.
- Kyriacou, O., Treasure, J. & Schmidt, U. (2008). Understanding How Parents Cope with Living with Someone with Anorexia Nervosa: Modelling the Factors that are Associated with Carer Distress. *International Journal of Eating Disorders*, 41, 233-242.
- Latzer, Y., Ben-Ari, A. & Galimidi, N. (2002). Anorexia nervosa and the family: Effects on younger sisters to anorexia nervosa patients. *International Journal of Adolescent Medicine and Health*, 14, 275-281.
- Linacre, S.J. (2011). *The Wellbeing of Carers of People with Severe and Enduring Eating Disorders (SEED)*. Unpublished Manuscript, Academic Unit of Psychiatry and Behavioural Sciences, The University of Leeds, UK. Retrieved May 6, 2014, from <http://etheses.whiterose.ac.uk/2030/>
- Lively, S., Friedrich, R.M. & Rubenstein, L. (2004). The effect of disturbing illness behaviours on siblings of persons with schizophrenia. *Journal of the American Psychiatric Nurse Association*, 10, 222-232.
- Lukens, E.P., Thorning, H. & Lohrer, S. (2004). Sibling Perspectives on Severe Mental Illness: Reflections on Self and Family. *American Journal of Orthopsychiatry*, 74, 489-501.

- Martín, J., Padierna, A., Aguirre, U., Quintana, J.M., Hayas, C.L. & Muñoz, P. (2011). Quality of life among caregivers of patients with eating disorders. *Quality of Life Research*, 20, 1359-1369.
- Martín, J., Padierna, A., Aguirre, U., Gonzalez, N., Muñoz, P. & Quintana, J.M.. (2013). Predictors of quality of life and caregiver burden among maternal and paternal caregivers of patients with eating disorders. *Psychiatry Research*, 210, 1107-1115.
- Medical Research Council. (2007). *MRC Ethics Guide: Medical research involving children*. Retrieved 13 November 2012 from www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC002430
- Micali, N., Hagberg, K.W., Petersen, I. & Treasure, J.L. (2013). The incidence of eating disorders in the UK in 2000–2009: findings from the General Practice Research Database. *BMJ Open*, 3, [e002646]doi: 10.1136/bmjopen-2013-002646.
- National Institute for Health and Clinical Excellence (NICE). (2004). *Eating Disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders*. London: National Institute for Health and Clinical Excellence. Retrieved 16 July 2011 from guidance.nice.org.uk/CG9
- Perkins, S., Winn, S., Murray, J., Murphy R. & Schimdt, U. (2004). A qualitative study of the experience of caring for a person with bulimia nervosa. Part 1: the emotional impact of caring. *International Journal of Eating Disorders*, 36, 256-268.
- Perlick, D.A., Rosenheck, R.A., Clarkin, J.F., Sirey, J.A., Salah, J., Struening, E.L., *et al.* (2001). Adverse Effects of Perceived Stigma on Social Adaptation of Persons Diagnosed With Bipolar Affective Disorder. *Psychiatric Services*, 52, 1627-1632.

- Platt, S. (1985). Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales. *Psychological Medicine*, 15, 383-393.
- Raenker, S., Hibbs, R., Goddard, E., Naumann, U., Arcelus, J., Ayton, A., *et al.* (2013). Caregiving and Coping in Carers of People with Anorexia Nervosa Admitted for Intensive Hospital Care. *International Journal of Eating Disorders*, 46, 346-354.
- Reid, K., Flowers, P. & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18 (1), 20-23.
- Reijonen, J.H., Pratt, H.D., Patel, D.R. & Greydanus, D. E. (2003). Eating Disorders in the Adolescent Population: An Overview. *Journal of Adolescent Research*, 18, 209-222.
- Rethink. (2011). *Rethink Brothers and sisters: Introducing Rethink Sibs: a space for siblings affected by mental illness*. Retrieved 6 April 2013 from www.rethink.org/media/465838/Siblings%20Network%20report%202011.pdf
- Sanderson, S., Tatt, I.D. & Higgins, J.P. (2007). Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: A systematic review and annotated bibliography. *International Journal of Epidemiology*, 36, 666-676.
- Schmid, R., Schielein, T., Binder, H., Hajak, G. & Spiessl., H. (2010). The forgotten caregivers: Siblings of schizophrenic patients. *International Journal of Psychiatry in Clinical Practice*, 13, 326-337.
- Scottish Children's Research Network. (2012). *ScotCRN Guidance: Obtaining informed consent for clinical research in children and young people under 16 in Scotland*. 7.08.12 (Version 1). Retrieved 13 November 2012 from www.scotcrn.org/informed-consent/

- Smith, J.A. (1995). Semi-structured interviewing and qualitative analysis. In J.A. Smith, R. Harre & L. Van Langenhove (Eds.) *Rethinking methods in psychology* (pp.9–26). London: Sage.
- Smith, J.A. (2004). Reflecting on the development of IPA and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39-54.
- Smith, J.A. (Ed.) (2008). *Qualitative Psychology: A practical guide to research methods* (2nd edn). London: Sage.
- Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.
- Starks, H. & Trinidad, S.B. (2007). Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory. *Qualitative Health Research*, 17, 1372-1380.
- Tedeschi, R.G. & Calhoun, L.G. (2004). Posttraumatic Growth: Conceptual Foundations and Empirical Evidence. *Psychological Inquiry*, 15, 1-18.
- Tong, A., Sainsbury, P. & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19, 349-357.
- Treasure, J., Gavan, K., Todd, G. & Schmidt, U. (2003). Changing the Environment in Eating Disorders: Working with Carers/Families to Improve Motivation and Facilitate Change. *European Eating Disorders Review*, 11, 25-37.

- Treasure, J., Murphy, T., Szmukler, G., Todd, G., Gavan, K. & Joyce, J. (2001). The experience of caregiving for severe mental illness: a comparison between anorexia nervosa and psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 36, 343-347.
- Treasure, J., Sepulveda, A.R., MacDonald, P., Whitaker, W., Lopez, C., Zabala, M., *et al.* (2008). The Assessment of the Family of People with Eating Disorders. *European Eating Disorders Review*, 16, 247-255.
- Vandenbroucke, J.P., von Elm, E., Altman, D.G., Gotzsche, P.C., Mulrow, C.D., Pocock, S.J., *et al.* (2007). Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Explanation and Elaboration. *Epidemiology*, 18, 805-835.
- Varni, J.W., Seid M. & Rode, C.A. (1999). The PedsQL™: Measurement Model for the Pediatric Quality of Life Inventory, *Medical Care*, 37, 126-139.
- von Elm, E., Altman, D.G., Egger, M., Gotzsche, P.C. & Vandenbroucke, J.P. (2007). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies. *Bulletin of the World Health Organisation*, 85, 867-872.
- Ware Jr., J.E., Kosinski, M. & Keller, S.D. (1996). A 12-Item Short-Form Health Survey (SF-12): Construction of Scales and Preliminary Tests of Reliability and Validity. *Medical Care*, 34, 220-233.
- Ware Jr., J.E. & Sherbourne, C.D. (1992). The MOS 36-item Short-Form Health Survey (SF-36). *Medical Care*, 30, 473-483.
- Whitney, J., Murray, J., Gavan, K., Todd, G., Whitaker, W. & Treasure, J. (2005). Experience of caring for someone with anorexia nervosa: qualitative study. *The British Journal of Psychiatry*, 187, 444-449.

- Whitney, J., Haigh, R., Weinman, J. & Treasure, J. (2007). Caring for people with eating disorders: Factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders. *British Journal of Clinical Psychology*, 46, 413-428.
- WHO. (2004). *A Glossary of Terms for Community Health Care and Services for Older Persons*. Geneva: World Health Organisation.
- WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. *Psychological Medicine*, 28, 551-558.
- Winn, S., Perkins, S., Murray, J., Murphy R. & Schimdt, U. (2004). A Qualitative Study of the Experience of Caring for a Person with Bulimia Nervosa. Part 2: Carers' Needs and Experiences of Services and Other Support. *International Journal of Eating Disorders*, 36, 269-279.
- Winn, S., Perkins, S., Walwyn, R., Schmidt, U., Eisler, I., Treasure, J., *et al.* (2007). Predictors of Mental Health Problems and Negative Caregiving Experiences in Carers of Adolescents with Bulimia Nervosa. *International Journal of Eating Disorders*, 40, 171-178.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15, 215-228.
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J.A. Smith (Ed.) *Qualitative Psychology: A Practical Guide to Methods* (2nd edn) (pp.234-251). London: Sage.

- Yu, P. M.W. (2008). *Stress and Coping of Parents with Daughters with Eating Disorders: An Intervention of a Coping-Focussed Intervention Group*. Unpublished Manuscript, Department of Psychology, The University of Hong Kong, China. Retrieved May 6, 2014, from <http://hub.hku.hk/bitstream/10722/55142/3/FullText.pdf>
- Zabala, M.J., Macdonald, P. & Treasure, J. (2009). Appraisal of Caregiving Burden, Expressed Emotion and Psychological Distress in Families of People with Eating Disorders: A Systematic Review. *European Eating Disorders Review*, 17, 338-349.

6. Appendices

6.1 Appendix A – International Journal of Eating Disorders Author Guidelines

(Formatting adjusted to assist with presentation)

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ORIGINALITY

The journal accepts for review manuscripts that have not been published or are not currently elsewhere under review.

CONTENT TYPES

Manuscripts published by IJED include: (1) Original Articles; (2) Brief Reports; (3) Critical analysis and Synthesis (reviews, articles on methodology or theoretical articles); (4) Commentaries; (5) Clinical Case Reports; (6) "An Idea Worth Researching;" and (7) Letters to the Editor. All word limits relate to the body of the text (i.e., not including abstract, references, tables or figures). These are maximum lengths, and authors are encouraged to keep their reports as short as possible while communicating clearly. The review criteria will include appropriateness of length.

To summarize, the article types are:

(1) Empirical Articles reporting substantive research that is novel, definitive or complex enough to require a longer communication.

Word Limit: 7,000 words, excluding abstract, references, tables and figures

Abstract: 250 words

References: 40

Figures/Tables: a maximum of 8 essential tables/figures, overall

(2) Brief Reports of research that can be communicated relatively succinctly, including straightforward research designs, pilot studies and replications.

Word Limit: 1,500 words, excluding abstract, references, tables and figures

Abstract: 200 words

References: 20

Figures/Tables: a maximum of 2 essential tables/figures, overall

(3) Critical Analysis and Synthesis/Review articles critically review the status of a given research area and propose new directions for research and/or practice. Both narrative and meta-analytic review papers are welcomed if they review a literature that is advanced and/or developed to the point of warranting a review of existing studies. Reviews of topics with a limited number of studies are unlikely to be deemed as substantive enough for a Critical Analysis and Synthesis Review paper.

Word Limit: 7,000 words, excluding abstract, references, tables and figures

Abstract: 250 words

References: 100

Figures/Tables: no maximum, but should be appropriate to the material covered

(4) Commentaries are written only at the invitation of the Editors, when multiple perspectives on or critical appraisal of an article would assist in placing that article in context.

Word Limit: 800 - 1,500 words, excluding abstract, references, tables and figures

Abstract: no abstract

References: 5, using the footnote format rather than the journal's standard format

Figures/Tables: none

(5) Clinical Case Reports detail key elements of cases where there is novelty in the presentation, pathology or treatment, and where that novelty will inform clinicians and researchers about rare presentations or novel ideas. This category will often be appropriate to rare biological or psychological presentations. Every effort should be taken to ensure the anonymity of the patient concerned, and any clinicians not involved as authors. If there is any potentially identifiable information, then it is the responsibility of the authors to seek and obtain approval from the local Institutional Review Board (IRB) (or equivalent) for the case to be reported, and a copy of that approval should be made available to the Editor on request.

Word Limit: 3,000 words, excluding abstract, references, tables and figures

Abstract: 150 words

References: 20

Figures/Tables: a maximum of 2 essential tables/figures, overall

(6) "An idea Worth Researching" is a format where authors propose an idea that may not yet have adequate empirical support or be ready for full empirical testing, but hold great promise for advancing our understanding of eating disorders. Authors are encouraged to write a piece that is bold, forward looking, and suggestive of new and exciting avenues for research and/or practice in the field.

Word Limit: 1,500 words maximum, excluding abstract, references, tables and figures

Abstract: no abstract

References: 5 maximum, in footnote format

Figures/Tables: a maximum of 2 essential tables/figures, overall

(7) Letters to the Editor should address key issues raised by articles in the previous edition of the journal. To facilitate such dialogue, letters need to be submitted within one week of the edition of the journal that they refer to.

Word Limit: 500 words maximum

Abstracts: no abstract

References: 3 maximum, in footnote format.

Figures/Tables: None

PREPARATION OF MANUSCRIPT & MANUSCRIPT FORMAT

General Format

Manuscripts must be typed in English and double-spaced throughout, with margins of at least one inch at the top, bottom, and both sides of each page. All manuscripts are subject to copyediting; however, it is the primary responsibility of the authors to proofread thoroughly and ensure correct spelling and punctuation, completeness and accuracy of references, clarity of expression, thoughtful construction of sentences, and legible appearance prior to the manuscript's submission. Preferred spelling follows Webster's New Collegiate Dictionary or Webster's Third New International Dictionary. The manuscript should conform to accepted English usage and syntax. Use headings to indicate the manuscript's general organization. Do not use a heading for the introduction. In general, manuscripts will contain one of several levels of headings. Centered upper case headings are reserved for Methods, Results, and Discussion sections of the manuscript. Subordinate headings (e.g., the Participants or Procedure subsection of Methods) are typed flush left, underlined, in upper case and lower case letters. The text begins a new paragraph. Number all pages of the manuscript except the figures (including title page and abstract) consecutively. Manuscripts that do not conform to the author guidelines stated here will be unsubmitted.

Number all pages of the manuscript except the figures (including title page and abstract) consecutively. Parts of the manuscripts should be arranged in the following sequence:

(1) Title page. (numbered 1) Titles should be short and specific, conveying the main point of the article. The title page should include the full names, titles, and affiliations of all authors, and an abbreviated title (Running Head) that should not exceed 50 characters, counting letters, spacing, and punctuation. The Running Head should be typed in upper case letters centered at the bottom of the title page. Each page of the manuscript (excluding figures) should be identified by typing the first two or three words of the full title in the upper right-hand corner above the page number. No running head is required for letters to the editor. Indicate the word count for the abstract and the word count for the manuscript (excluding figures, tables, and references).

(2) Abstract. (word maximum varies by article type) For article types requiring an abstract, the abstract should be typed as a single paragraph on a separate page, numbered 2. Type the word "Abstract" in upper and lower case letters, centered at the top of page 2. Provide the following information in the form of a structured abstract, using these headings: **Objective:** briefly indicate the primary purpose of the article, or major question addressed in the study. **Method:** indicate the sources of data, give brief overview of methodology, or, if review article, how the literature was searched and articles selected for discussion. For research based articles, this section should briefly note study design, how participants were selected, and major study measures. **Results:** summarize the key findings. **Discussion:** indicate main clinical, theoretical, or research applications/implications. The *Journal* requires structured abstracts with one exception: the *Journal* will continue to use unstructured abstracts for case reports.

(3) Text. Begin the text on page 3 and be sure to identify each page with the short title typed in the upper right-hand corner above the page number. Type the full title of the manuscript centered at the top, and then begin the text. The full title appears on page 3 only. Indent all paragraphs. The maximum length for article submissions is specified for each manuscript type. Authors are advised that content be conveyed as concisely as possible.

(4) References. Begin on separate page, with the word "References" typed in upper and lower case letters, centered at the top of the page. References must be double spaced.

(5) Appendices. Type each appendix on a separate page labeled "Appendix A, B", etc., in the order in which they are mentioned in the text.

(6) Footnotes. Start on separate page.

(7) Tables. Tables should be double-spaced, including all headings, and should have a descriptive title. If a table extends to another page, so should all titles and headings. Each table should be numbered sequentially in Arabic numerals and begin on a new page. Be sure to explain abbreviations in tables even if they have already been explained in-text. Consider the tables and figures to be self-contained and independent of the text. They should be interpretable as stand-alone entities.

(8) Figure captions. Start on separate page. Each figure caption should have a brief title that describes the entire figure without citing specific panels, followed by a description of each panel. Figure captions should be included in the submitted manuscript as a separate section. Be sure to explain abbreviations in figures even if they have already been explained in-text. Consider the tables and figures to be self-contained and independent of the text. They should be interpretable as stand-alone entities. Axes for figures must be labeled with appropriate units of measurement and description.

(9) Acknowledgements/Disclosure of Conflicts. Start on a separate page. Any possible conflict of interest, financial or otherwise, related to the submitted work must be clearly indicated in the manuscript. Acknowledge significant contributions that do not warrant authorship; list sources of support (e.g., federal, industry, or other funding).

Informed Consent

The Methods section should include a statement that the research was reviewed and approved by an institutional review board, and that participation involved informed consent.

Every effort should be taken to ensure the anonymity of the patient concerned, and any clinicians not involved as authors. If there is any potentially identifiable information, then it is the responsibility of the authors to seek and obtain approval from the local Institutional Review Board (IRB) (or equivalent) for the case to be reported, and a copy of that approval should be made available to the Editor on request.

Presenting Statistical Data in Text

For additional detail regarding statistical requirements for the manuscript see [IJED Statistical Formatting Requirements](#). For more detailed background information on statistical analyses and their rationale authors are referred to [IJED Statistical Reporting Guidelines](#).

References

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Journal Article: 1. Endicott J, Spitzer RL. A diagnostic interview: The schedule for affective disorders and schizophrenia. Arch Gen Psychiatry 1978;35:837-844.

Book Chapter: 2. Fairburn CG, Cooper Z. The eating disorders examination (12th ed). In: Fairburn CG, Wilson GT, editors. Binge eating: nature, assessment, and treatment. New York: The Guilford Press, 1993, p. 317-331.

Book: 3. Tudor I. Learner-centeredness as language education. Cambridge: Cambridge University Press; 1996.

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- 300 dpi for halftones (black and white photographs)
- 600 dpi for combination halftones (photographs that also contain line art such as labeling or thin lines)

Vector-based figures (usually created in Adobe Illustrator) should be submitted as EPS. Do not submit figures in the following formats: JPEG, GIF, Word, Excel, Lotus 1-2-3, PowerPoint, PDF.

Graphs must show an appropriate grid scale. Each axis must be labeled with both the quantity measured and the unit of measurement. Color figures must be submitted in a CMYK colorspace. Do not submit files as RGB. All color figures will be reproduced in full color in the online edition of the journal at no cost to authors. Authors are requested to pay the cost of reproducing color figures in print. Authors are encouraged to submit color illustrations that highlight the text and convey essential scientific information. For best reproduction, bright, clear colors should be used.

Supplementary materials. Supplementary materials will be made available to readers as a link to the corresponding articles on the journal's website.

ADDITIONAL GUIDELINES FOR COPYEDITING OF MANUSCRIPTS FOR INTERNATIONAL JOURNAL OF EATING DISORDERS

1. Some authors use terms such as “anorexics” or “bulimics” as personal pronouns, referring to groups of individuals by their common diagnosis. Language of this type should be replaced with such

terms as “individuals with anorexia nervosa”, “people with bulimia nervosa”, or “participants with eating disorders”.

2. The term “participants” should be used throughout the article instead of “subjects”.

3. Standard rules will continue to govern the use of capitalization in Headings and Subheadings. However, when a minor word in a Heading or Subheading actually has special or unique meaning, the rule should be overridden.

4. When referring to gender, “males” and “females” should be used in cases where the study samples include both children (below age 18) and adults; when the participants comprise adults only, the terms “men” and “women” should be used. In articles that refer to children (i.e., below the age of 13), “boys” and “girls” should be used.

5. In articles that refer to genetic material, the names of genes should be spelled out in full the first time they appear in the text, after which an italicized abbreviation can be substituted.

6. The word “data” is plural; therefore, text should follow accordingly (for example, “The data show...the data are ... the data were...”).

7. For information on how to present *p* values and other standard measurements see [JED Statistical Formatting Requirements](#)

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Prepare your manuscript and illustrations in appropriate format, according to the instructions given here.

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Please be sure to study the Instructions and Forms given at the site carefully, and then let the system guide you through the submission process. Online help is available to you at all times during the process. You are also able to exit/re-enter at any stage before finally "submitting" your work. All submissions are kept strictly confidential. If you have any questions, do not hesitate to contact us at support@scholarone.com.

REVIEW

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Editorial Pre-Screen. The Editor-in-Chief will pre-screen all submissions to determine articles' suitability based on fit with the journal's scope and scholarly merit. Articles deemed to fall outside of the journal's scope or to be of limited merit (e.g., because of substantial methodological flaws or

insufficiently novel contribution to the field) will not be sent out for peer review. Pre-screening of articles does not involve detailed evaluation.

Peer Review. Submissions that, based on editorial pre-screening, are considered of potential suitability for the journal are forwarded to members of the editorial board (and, on occasion, outside experts) for detailed evaluation and feedback. Expert reviewers are asked to evaluate the merit of an article based on the quality of methods applied, presentation, and overall contribution to the field. Reviewers are instructed to offer a thorough, constructive, and timely evaluation of all aspects of the article and to enumerate strengths and weaknesses. Authors are invited to recommend expert reviewers.

Exceptions to the peer-review procedures described above are made in the case of a) Letters to the Editor which, rather than being forwarded for additional peer review, are evaluated only by the Editor and one Associate Editor, and b) Commentaries, which are evaluated only by the action editor and one additional reviewer.

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6.2 Appendix B – STROBE Statement Guidelines

STROBE Statement—checklist of items to be included in reports of observational studies

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	<p>(a) <i>Cohort study</i>—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up</p> <p><i>Case-control study</i>—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls</p> <p><i>Cross-sectional study</i>—Give the eligibility criteria, and the sources and methods of selection of participants</p> <p>(b) <i>Cohort study</i>—For matched studies, give matching criteria and number of exposed and unexposed</p> <p><i>Case-control study</i>—For matched studies, give matching criteria and the number of controls per case</p>
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why

Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding
		(b) Describe any methods used to examine subgroups and interactions
		(c) Explain how missing data were addressed
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed
		<i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed
		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy
		(e) Describe any sensitivity analyses

Results

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(b) Report category boundaries when continuous variables were categorized
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Discussion

Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results

Other information

Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based
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*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

6.3 Appendix C – Qualitative Health Research Journal Author Guidelines

(Abridged author guidelines and formatting adjusted to assist with presentation)

Qualitative Health Research - An International, Interdisciplinary Journal

QHR MANUSCRIPT GUIDELINES SEPTEMBER, 2011

NOTE TO AUTHORS:

If answers to your questions are not found within the Guidelines, please address your inquiries to QHR-Journal@nurs.utah.edu (please do not send inquiries to other/additional QHR email addresses). You may also telephone our office at 801-585-5378. Thank you for your cooperation.

ABOUT QUALITATIVE HEALTH RESEARCH (QHR)

Editor: **JANICE M. MORSE, RN, PHD (ANTHRO), PHD (NURS), FAAN** University of Utah College of Nursing, Salt Lake City, Utah, USA

QUALITATIVE HEALTH RESEARCH, widely referred to as **QHR**, is an international, interdisciplinary, refereed journal for the enhancement of health care. Published monthly, it is designed to further the development and understanding of qualitative research methods in health care settings. The journal is an invaluable resource for researchers, practitioners, academics, administrators, and others in the health and social service professions, and graduate students who seek examples of qualitative methods.

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We also consider critical reviews; articles addressing qualitative methods; and commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.

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[REV 6: 01 SEP 11]

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If you would like to join the review board for *QHR*, please email your curriculum vitae (CV) and complete contact information to QHR-Journal@nurs.utah.edu.

Thank you! We look forward to hearing from you! Janice M. Morse, Editor

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PERMISSIONS

By mail/post: Mail the completed document to: Dori Fortune

University of Utah College of Nursing 10 S. 2000 E. Salt Lake City UT 84112-5880 USA

☐ Note that the *corresponding author* completes and signs the form on behalf of all co-authors of a particular manuscript; it is not necessary to obtain the signature of each author. Remember that all author names must appear on the first page of the form. *Please print legibly!*

☐ Submit only the first 2 pages of the completed form.

☐ Do not submit a completed *Exclusive License to Publish* form unless and until you receive word that your manuscript has been accepted for publication.

GENERAL INFORMATION

This section of the Guidelines covers matters of *QHR* journal style, which are not subject to author preference; adherence is required. **Note:** If you still have questions after carefully reading these instructions, please refer to the sample manuscripts (there are several types) beginning on page 35 before contacting the *QHR* office.

IMPORTANT CONSIDERATIONS

☐ *Qualitative Health Research* is a peer-reviewed journal. Only complete, finished manuscripts should be submitted for consideration.

☐ We do not publish stand-alone abstracts, *quantitative* studies, manuscript outlines, pilot studies, manuscripts-in-progress, letters of inquiry, or literature reviews. Research articles *must be pertinent to health*.

☐ Write both the abstract and the text of your manuscript in *first-person, active voice*.

☐ For best results, review this entire document prior to preparing and submitting your manuscript.

- Proper manuscript preparation will speed the peer-review process for your manuscript, and will facilitate a smoother production process if it should be selected for publication.
- Improper manuscript preparation could result in burdensome revisions, lengthy delays in the review and production processes, and the possible rejection of your manuscript.

We ask authors considering submission to *QHR* to review these guidelines, survey several issues of the journal, and make their own decision regarding the “fit” of their article for *QHR*’s mission. *Please refrain from writing or calling to ask if we are interested in your particular manuscript or idea.*

In general, *QHR* adheres to the requirements of Sage Publications, Inc., and the guidelines contained in the ***Publication Manual of the American Psychological Association*** [“APA”], **6th edition** (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. Elsewhere in these Guidelines this book is referred to as the *APA Publication Manual*, or just *APA*. Additional help may be found online at <http://www.apa.org/>, or search the Internet for “APA format.”

Many universities and private organizations have Web sites devoted to *APA* style. However, when guidelines found on those sites, or in the *APA Publication Manual*, conflict with *QHR* Guidelines, *you must follow the QHR Guidelines.*

CONFIDENTIALITY AND PROTECTION OF IDENTITY

QHR is committed to protecting the identity and confidentiality of research study participants. With the exception of participatory action research (PAR), *no information* that could potentially allow identification of a participant—or even a *specific study site*—should be included in a submitted manuscript or, subsequently, included in a published article.

If the use of participant names is absolutely necessary for reader understanding, each study participant referred to in the manuscript should be assigned a pseudonym. Study sites, such as hospitals, clinics, or other organizations, should not be named, but instead should be described; for example: “Study participants were recruited from the coronary care unit of a large metropolitan hospital on the eastern seaboard of the United States.” Authors who include participant names and/or photos/images in which individuals are identifiable must submit written permission from the participants to do so—*no exceptions*. Permission to use photographs should contain the following verbiage: “Permission is granted to use, reproduce, and distribute the likeness/photograph(s) in all

media (print and electronic) throughout the world in all languages.” To protect author anonymity during the review process, author citations in the text should include only the word “Author” and the year: (*Author*, 2008). Author references in the reference list should also include only the word “Author” and the year: *Author*. (2008). (See the section on references for more details.)

WORD CHOICES

It is always best to use the most precise language possible to convey important data, concepts, and findings. Because *QHR* is an international journal published in U.S. English, there is the added need to avoid commonly used English terms (colloquialisms, slang) that might be misinterpreted by or confusing to readers whose first language is something other than English.

Word or Phrase Consideration

as Do not use this word when your meaning is *because*.

amongst Use *among* instead.

as regards Use *with regard to*, or *regarding* instead.

can’t, don’t, and so forth Use *cannot*, *do not*, and so forth. Do not use contractions unless they are part of a quotation.

Caucasian Use *White* instead, capitalized.

due to Use *because of* instead.

etc. Use *and so forth* instead.

feel It is appropriate to use this word when referring to a physical sense or state of mind; do not use it when your intent is *think* or *believe*.

female(s) Please use *woman* or *women* instead, whenever possible and appropriate.

firstly, secondly, thirdly Use *first*, *second*, and *third* instead.

further This word is appropriately used when referring to distance, or perhaps with respect to “furthering” something. At the beginning of a new sentence, when writing of something in addition to

something already stated, it is more appropriate to use *furthermore*, *moreover*, *in addition*, or *additionally*.

Importantly Do not use this word unless it is part of a quotation.

in order to Use *to* instead. Interestingly Do not use this word unless it is part of a quotation.

lastly Use *last* or *finally* instead.

male(s) Please use *man* or *men* instead, whenever possible and appropriate.

may Do not use this word in place of *might*. Use *may* for permission, *might* for possibility, and *can* for ability.

on the one hand / on the other hand Do not use these terms in your writing.

over Do not use this word when the intended meaning is *more than*.

paper Use *article* instead.

since *Since* is the appropriate word to use when referring to the passage of time; do not use it when your intended meaning is *because*.

towards Use *toward* instead.

upon Use *on* instead

U.S./United States

Use *U.S.* only as an adjective; in all other instances, spell out *United States*.

The same rule applies to *UK/United Kingdom*.

while/whilst Use *while* when referring to concurrent events; do not use it when your intent is *whereas*, *although*, or *even though*. Do not use *whilst*.

COMMON PROBLEMS

Acronyms - The full spelling of the related words must precede the first usage of an acronym (even if you think everyone knows what the acronym stands for), followed by the acronym in parentheses; e.g., *World Health Organization (WHO)*. Thereafter you may use the acronym alone: *WHO*. Avoid the overuse of multiple acronyms.

Anthropomorphism occurs when human characteristics are attributed to things not human. For example: *This study used a grounded theory approach . . .* Obviously, a study cannot “use” anything. It would be more appropriate to write, *In this study we used a grounded theory approach . . .* Eliminate anthropomorphism from your manuscript.

Back-to-back parentheses Incorrect: (xxx) (yyy) / Correct: (xxx; yyy)

Bad beginnings Do not begin sentences—and especially paragraphs—with *and*, *yet*, or *but*. Use caution when beginning a sentence, and do not begin a paragraph, with *however*.

Capitalization Capitalize proper names. Do not capitalize words unnecessarily, such as titles and ranks (e.g., director, professor, doctor, chairperson), or themes, categories, concepts, and so forth. (See also Title Case, below)

Ellipses Ellipses (. . .) are to be used only to represent words missing from quotations. Do not use them to represent pauses in speech.

Hyphenation Refer to the *APA Publication Manual*, 6th edition, for an excellent explanation of the proper use of hyphens and dashes; *do not* depend on Word’s “Spell Checker” feature for decisions on hyphenation. With few exceptions (see *APA*), words beginning with *co*, *non*, *pre*, *post*, *re*, *semi*, *socio*, and *sub* do not require hyphenation.

Horizontal lines Do not place horizontal lines in your manuscript. If footnote separator lines appear, remove them.

Inconsistent writing style When reviewing your manuscript prior to submission, watch for inconsistent writing style. This is especially important for manuscripts having two or more authors.

Irrelevant data Page space in the journal is precious. Refrain from including interesting but irrelevant data or commentary.

Jargon *QHR* readers come from a wide variety of disciplines and backgrounds, and therefore might not be familiar with the terminology related to your particular field or discipline. If you must include

jargon, be sure to explain it clearly the first time a discipline-specific word is used. Avoid the overuse of jargon.

Non-English words The first time a non-English word is used, italicize it. Thereafter, use only Roman font. All non-English words must be explained or defined in the text. Include English translations of all non-English titles in the reference list (refer to *APA* for instruction on how to do this).

Paragraph length To facilitate ease of reading, paragraphs should be no longer than one half of a double-spaced, 8.5 x 11-inch page. Avoid paragraphs of only two or three sentences in length; combine them as necessary to make paragraphs of more appropriate length.

Participant characteristics Under no circumstances should you include individual participant characteristics in your manuscript. Group participant characteristics. In most cases it is best to write group characteristics into the text rather than placing them in a table (use whichever format takes the least amount of page space).

Repetition Avoid it! Make your writing as “tight,” precise, and concise as possible. Avoid including the same facts, conclusions, or information in multiple places in the text (this does not mean you cannot summarize, of course). Avoid overuse of the same phrases, and avoid repeating certain characteristics of your sample; for example: *Twelve-year old boys are perceived as . . . This is often a problem for 12-year-old boys. Also, 12-year-old boys are . . .*

Run-on sentences Avoid long, wordy, complex sentences.

Spacing Use *no spaces* before, and only a *single space after* periods (.), commas (,), colons (:), semicolons (;), question marks (?), and closing quotation marks ("). All line spacing (except for text within figures) should be set at *exactly* double, with 0" before and 0" after.

Special formatting *Never* use *any* coding or formatting in your manuscript that is not called for in these Guidelines.

Spelling *QHR* is published in U.S. English. For best results, set the language of your document to U.S. English when you are establishing all other document setup requirements. Note the correct spelling of a few commonly misspelled words: *health care* (two words); *keywords* (one

word); *semistructured* (one word, no hyphen). Also, refer to the section on hyphenation, above. *QHR* uses *Merriam-Webster's Collegiate Dictionary* (2005) as our spelling reference.

Title Case Title case is properly created by capitalizing:

- ☐ the first letter of the first word
- ☐ the first letter of the first word after a colon (:), period (.), or dash (—)
- ☐ all important words, and
- ☐ *all words containing four or more letters*

Verb tense Things that happened, were said, or were written in the past should be written about in the past tense. When writing about what is included in your article, use the present tense rather than the future tense (e.g., *In this article we present*, rather than *In this article we will present*).

Research studies and articles about research studies are two separate things. Do not confuse the meaning of these words in your writing.

BASIC DOCUMENT PREPARATION

See also a variety of sample manuscripts beginning on page 35.

Note: Do not use any coding or formatting that is not described within these Guidelines!

DOCUMENT SETUP AND FORMATTING

Document file type Submit *only* documents created in **Microsoft Word**, and only with the regular file extension of **.doc** or **.docx** (do not submit documents with *.docm*, *.rtf*, *.pdf* or other extensions).

Paper size Letter, 8.5 x 11 inches, with portrait orientation

Margins 1 inch (1"; approximately 2.5 cm.) on all sides

Line numbers None

Line spacing Exactly “double,” with 0" before and 0" after

ORDER OF MANUSCRIPT ELEMENTS

Compile the elements of your manuscript in the following order:

Document 1:

Title page (required)

Document 2:

Abstract and keywords (required)

Main manuscript text (required)

Notes (if any)

References (required)

Appendices (if any)

Tables (if any)

Document 3:

Figure 1 (if any)

Document 4:

Figure 2 (if any; and so forth, with each subsequent figure in a separate document)

FORMATTING OF MANUSCRIPT ELEMENTS

Note: For ease in locating needed information, the various elements are listed below in alphabetical order, and not in the order of anticipated use. Dialogue Presentation of participant dialogue (i.e., two or more “speakers”) should be set as block quotes/excerpts, indented by ½ inch (approximately 1.3 cm.) from the left margin. Do not use bullets or hanging paragraphs. Begin the narrative of each speaker on a new line. The first time a speaker name is used, type it in full, followed by an appropriate abbreviation in parentheses prior to the colon; thereafter, use only the abbreviation for the speaker name. Refer to the sample manuscripts for an example of dialogue presentation.

Ellipses / ellipsis points

Almost every manuscript contains ellipses. They are used to indicate words missing from quotations, and are to be created in a very specific manner. The proper way to create ellipsis points is as follows:

Three (3) dots, preceded, divided, and followed by spaces (i.e., SPACE.SPACE.SPACE.SPACE), like . . . this. If it is necessary to indicate missing words between sentences (instead of in midsentence):

Place a period (full stop) at the end of the first sentence, then format the ellipsis points as noted, and begin the next sentence (with a capital letter) immediately after the last space (i.e., .SPACE.SPACE.SPACE.SPACE). . . .

Italics should be used only

- ☐ as appropriate in the reference list (see *APA*);
- ☐ as appropriate in level-2, -3, and -4 headings; and
- ☐ to introduce non-English words, or *unusual* new concepts (2 to 3 words), and then only when the new word or concept is first introduced in the manuscript; subsequent use of the same word(s) should be in regular Roman font.

Headings All headings, without exception, are to be set in Gill Sans, 12-point font. (Use Arial if you do not have Gill Sans on your computer.) #QHR uses 4 distinct levels of headings (H = Heading), including: H Level Formatting (Note: All headings should be double-spaced, just like the regular text) H1 **Flush Left, Bold Text, in Title Case** H2 *Flush Left, Italicized Text, in Title Case* H3 *Flush left, italicized text, in sentence case, ending with a period.* At this level, the paragraph text begins immediately after the heading, instead of on the next line. The heading is part of the paragraph. Use this heading only if you have a total of four (4) heading levels. **Note: Try to avoid the use of H3 if possible, and use only H1, H2, and H4 (see below).** H4 *Indented (.5" or 1.3 cm.), italicized text, in sentence case, and ending with a period.* At this level, the paragraph text begins immediately after the heading, instead of on the next line. The heading is part of the paragraph.

Use *at least two* heading levels:

For manuscripts with 2 heading levels, use H1 and H2

For manuscripts with 3 heading levels, use H1, H2, and **H4** [not H3]

For manuscripts with 4 heading levels, use H1, H2, H3, and H4

Be aware of limitations on the use of heading levels H2, H3, and H4: You are not required to use an H2 heading below any given H1 heading, but if you do, you must use two or more H2 headings; you cannot use just one. The same is true for H3 headings below any given H2 heading, and for H4 headings below any H2 or H3 heading.

Justification of margins

All text should be *left justified*.

Length of manuscript

There is no predetermined word or page limit. Provided they are “tight” and concise, *without unnecessary repetition* and/or irrelevant data, manuscripts should be as long as they need to be.

The editor might require a reduction in length if the manuscript contains material that does not add anything useful to the topic being discussed. Limits might be imposed on the number/size/length of tables, figures, reference lists, and appendices.

Line spacing ***Everything***, in all elements of the manuscript, from the title page through the references and tables (if any), must be exactly double spaced. The only exception: Text within a figure should be single spaced.

Lists Vertical lists (i.e., listed down the length of the page) should be either simple dot bullets or bullets numbered 1., 2., 3., and so forth. Leave a blank, double-spaced line after all lists.

Paragraphs Paragraphs are to flow, one after the other, without additional line breaks (with few exceptions; see below), and with no extra space between paragraphs.

Leave a blank (double-spaced) line between the abstract and the keywords.

Leave a blank line *after* (not before) each block quote, numbered list, or bulleted list.

Leave a blank line between block quotes if you have placed two or more in succession.

Indent the first line of every new paragraph by ½ (.5) inch (approximately 1.3 cm.), *except*:

- ☐ the first line of the abstract or the keywords.
- ☐ the first (opening) paragraph of the manuscript text.
- ☐ paragraphs immediately after level-1 and level-2 headings.
- ☐ paragraphs beginning with level-3 headings.

Use Word's Format > Paragraph function to set paragraph first-line indentations, *but apply this paragraph by paragraph, and not to the entire document*.

Use Word's Format > Paragraph function to set block quote/excerpt and bulleted/numbered list indentations. Note that block quotes/excerpts and lists are to be *completely* indented (not just the first line) by .5 inches (approximately 1.3 cm.) from the left margin only; *do not indent from the right side*.

Quotation marks In general, use double quotation marks (e.g., “Xxxx.”) to set off quotations appearing within regular paragraphs, and to set off words being used with “special” meaning (or unusual spelling to convey special meanings within the text; e.g., “busy-ness”). Do not use quotation marks around quotations presented as block quotes/excerpts.

In regular paragraphs, use single quotation marks to set off a quote within a quote (e.g., “Xxx, ‘Yyy,’ xxxx.”).

Note that when *closing* quotation marks coincide with a comma or period (full stop), the quotation marks go outside (after) the comma or period: “Quotation. . . last word.”

Quotations of fewer than 40 words should be surrounded by double quotation marks (”) and included within the regular sentences of a paragraph. Internal quotations within quotations of fewer than 40 words should be set apart with single quotation marks (’).

Quotations of 40 or more words should be set as separate paragraphs, with the entire quotation indented .5 inches (approximately 1.3 cm.) from the left margin (this is also referred to as a “block quote” or “excerpt”). Do not use quotation marks for block quotes unless there is a separate, internal

quotation within the larger quotation; in that case, use double quotation marks (") for the internal quotation only. *Make sure all quotations are properly capitalized and punctuated.*

Format the indentation for block quotes with Word's Format > Paragraph feature.

See the special section, below, for instructions on formatting *conversation analysis*.

Seriation refers to "numbered" lists appearing in sentences of regular text (in other words, across the page rather than in a vertical list). The proper seriation style for manuscripts submitted to *QHR* is (a), (b), (c), and so forth (lowercase letters, enclosed in parentheses).

Spelling See "Common Problems," above. Exceptions to the use of U.S. English include

(a) direct quotes from *written, published material*, and (b) titles in the reference list (which should be spelled exactly as published).

"REVIEW" YOUR MANUSCRIPT

One common reason for "revise" decisions is that authors are sometimes so immersed in their data and findings that they lose track of

- ☐ whether the information presented contributes new knowledge
- ☐ whether the appropriate method and design have been used
- ☐ whether ethical standards have been met
- ☐ whether the information is presented in a complete, concise, and logical manner, with attention to writing style, and
- ☐ what the reader needs/wants to know (remember that *QHR* readers have expertise in diverse areas, and therefore many will not be familiar with concepts and terminology common to your research area)

Before submission, we recommend an informal peer review of your article, using the criteria shown on page 55.

PRIOR TO SUBMISSION (removed)

QHR KEYWORD LIST (lists removed)

Note: We recommend reading the entire list to identify the most relevant keywords. Remember that the keywords might not be listed exactly the way you think of them (the specific words and the order of words might be different).

ELEMENTS OF A MANUSCRIPT

*Note: Some instructions differ for **accepted** manuscripts; please refer to page 28.*

The following elements are **required** for each manuscript, and should be compiled in the following order:

Title page - Submit the title page as a *separate document*.

Abstract - The abstract is placed on page 1 of the main document.

Keywords - Place the keywords below the abstract, on the same page. Leave a (double-spaced) blank line between the abstract and the keywords.

Main manuscript

The main text of the manuscript begins on page 2 of the main document.

References begin on a new page, after the end of the manuscript text, or after the notes, if any (*do not* submit references in a separate document).

The following elements are **optional**, and may be included in your submission:

Notes Place notes (also known as endnotes) after the main text, before the first page of references.

Tables Place tables, *one per page*, at the end of the main manuscript document, after the references (do not submit tables as separate documents).

Figures Submit each figure in a *separate document*, in order, by number.

Appendices are published *only at the editor's discretion*. Place any appendices after the reference list, and before any tables (place them before the bios in accepted manuscripts).

MANUSCRIPT PREPARATION

PREPARATION OF MANUSCRIPT ELEMENTS

A maximum of four (4) *types* of documents should be submitted: (a) title page; (b) main manuscript; (c) figures (if any); and (d) permissions (if needed). Despite what the online submission system (ScholarOne Manuscripts / SageTrack) might allow, *do not submit such elements as abstracts, references, and tables in separate documents*. Be sure to refer to the sample manuscripts, beginning on page 35.

TITLE PAGE

The title "page" may be longer than one page. To maintain author anonymity during peer review, it is submitted as a *separate document*. Title page information *should not be included* in the main manuscript document. *Do not format a running header*. The title page should include the following, *in this order*:

Article title

A title should convey, as clearly and *succinctly* as possible, the main idea, focus, or content of a manuscript. It should be clear in meaning even when standing alone. Make your title 10 to 12 words (or fewer) in length; avoid long, "wordy" titles. Avoid titles with colons or quotations unless they are *necessary* to convey an important concept or idea in the article.

Type your title in *Title Case*; this means you should:

- * capitalize the (first letter of) the first word
- * capitalize all important words
- * capitalize *all words that have four (4) or more letters*
- * capitalize the first word after a colon (:), period (.), or em dash (—)

Author names List the name (not just initials) of each author, *without credentials*, in order, horizontally across the page. If there are two authors, list them as follows: Janice M. Morse and Author Two If there are three or more authors, list them as follows: Janice M. Morse, Author N. Two, Writer Three, and Fourth Author (and so forth)

After each name (or *after* the comma following a name, if applicable), use a superscript number to link that particular author with his or her *primary* affiliation (see the section on author affiliations, below).

Author affiliations Using the same superscript numbers as used with the authors' names (see above), list ***only the primary affiliation*** of each author, not multiple affiliations (see the sample manuscripts).

Spell out all city, state, and country names (exception: use USA instead of United States). Spell out any organization or institution names (for example, *University of Utah* instead of *U of UT*, or *World Health Organization* instead of *WHO*).

Corresponding author information - Use *only* the following format for the corresponding author information, and *do not* include any information that is not listed below. List information only for the individual who should be contacted by readers after (if) the article is published.

Note that this should be a *complete mailing/postal* address. Example: Janice M. Morse, University of Utah College of Nursing, 10 S. 2000 E., Salt Lake City, UT 84112-5880, USA Email: QHR-Editor@nurs.utah.edu

Authors' Note - *This is optional*. This is the place to mention, perhaps, that portions of the article were presented at a professional meeting, or other information of that sort.

Acknowledgments - *This is optional.* The section is limited to two (2) or three (3) *brief* sentences. Overlong acknowledgments will be reduced at the copyeditor's discretion. Do not include long descriptions of persons being acknowledged, and do not include roles, titles, or credentials. Avoid phrases such as *We wish to thank*, *We would like to thank*, and *We want to thank*; just use a simple, *We thank*, or *We acknowledge*.

Declaration of conflicting interests

You must use one of the following statements, *in the exact words* shown below.

If you have no conflicts of interest (or potential conflicts of interest): The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

If you have conflicts of interest: The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: [Then, **in sentence form**, list all specific author relationships with organizations and/or products that were declared].

Funding

You must use one of the following statements, *in the exact words* shown below.

If you did not have financial support: The author(s) received no financial support for the research, authorship, and/or publication of this article.

If you did have financial support: The author(s) disclosed receipt of the following financial support for the research, authorship, and or publication of this article: [Then list, **in sentence form**, all entities/organizations that funded the research and/or authorship].

Bios

Bios are *simple and concise*, 1-sentence statements about each author. Long bios will be reduced by the copyeditor. In this space you may include department or division names, and secondary affiliations (if any). Use only the format shown below for your bios. Note that *primary credentials* (the *most important* only, with a limit of three per person; *QHR* does not publish long credential strings) and *current* positions (or affiliations or professional pursuits) are *required*.

Janice M. Morse, PhD, FAAN, is a professor and presidential endowed chair at the University of Utah College of Nursing in Salt Lake City, Utah, USA. [Template: **Name, bolded**, credentials, role or title, affiliation (here you may include department, school, division, and so forth), city, state or province (if any), country.]

ABSTRACT AND KEYWORDS

The abstract should be placed at the top of page 1 of the main manuscript document. It should be a single paragraph, no more than 150 words in length, and briefly describe your article. It should not contain headings or citations, and should not be divided into sections. Place your keywords below the abstract, on the same page (see "Keywords," above). Double space the entire abstract page (including the keywords). Briefly state the purpose of your research, the main findings, and your primary conclusions. Make sure the abstract is written in the first-person, active voice.

MAIN MANUSCRIPT

Note that the sample manuscripts beginning on page 35 are abbreviated for illustration purposes, and might not contain all optional elements that could be included in an actual manuscript. The sample articles contain all four heading levels.

The main text of the manuscript begins at the top of page 2 of the document, immediately after the abstract page. *Write your article in the first-person, active voice.*

The main text of the manuscript should be broken into appropriate sections by the use of section headings. Sections should flow in a logical sequence, and include, at a minimum, *Methods*, *Results*, and *Discussion* (these are all level-1 headings); other level-1 headings and subheadings may be used at the author's discretion. The author may choose to use different names for the three main sections, but the basic content should be that which would appropriately fall under the headings of *Methods*, *Results*, and *Discussion*.

There are very specific requirements for the preparation of in-text citations; refer to the *APA Publication Manual*, 6th edition, for details. Every in-text citation should have a corresponding reference in the reference list—*no exceptions*.

During the review process, author citations should include only the word *Author* and the year: (*Author*, 2008). If and when the manuscript is accepted for publication, the missing information can be restored.

Double space the entire manuscript document, *except for text contained in figures*. Use only U.S.-English spelling (except in the references, as appropriate, and for direct quotations from published written sources). Use U.S.-English translations of non-English quotations or excerpts. Use a minimum of two (2) heading levels.

Attend to copyright regulations and permission requirements (*required*). Submit, at the time of manuscript submission, written permission for the use of any names, photographs, or copyrighted tables, figures, and/or text; written permission must come from the person(s) depicted in the photographs, or in the case of copyrighted work, from the copyright holder (which is not necessarily the author or the journal in which it is published; see page 7).

REFERENCES

Note: Proper formatting of the reference list is the responsibility of the *author*, NOT journal personnel. The reference list (also known as a bibliography) should include complete references for the sources used in the preparation of your manuscript. *Every reference* must be cited in the text.

The reference list should begin on a separate page (not in a separate document) following the last page of manuscript text (or after the notes, if any). Each type of reference (journal article, book, chapter in edited book, newspaper, online reference, and so forth) must be formatted in accordance with the precise guidelines contained in *APA*, 6th edition.

Elements such as listing order, spelling, punctuation, spacing, capitalization, and the use of italics or Roman (regular) font are as important as the content of the reference. Note that if an author has two or more initials, there should be spaces between the initials; incorrect = X.Y.Z.; correct = X. Y. Z.

References should be listed in hanging paragraph format (with indentations at ½ inch or 1.3 cm.), in alphabetical order by the last name of the first author; additional considerations might apply (see *APA*). The hanging paragraphs should be created by using Word's Format > Paragraph feature.

During the review process, author references in the reference list should include only the word "Author" and the year: *Author. (2008)*. To prevent author identification during the review process, do not include the article title, journal name, or any other part of the reference. Do not place these references in alphabetical order in the reference list; place them at the very beginning or very end of the list. If and when the manuscript is accepted for publication, the missing information can be restored and properly placed.

Avoid the use of unnecessary references and lengthy reference lists. Extensive bibliographies will not be published; articles should include only the "essential" or key references. If the author wishes to offer a secondary reference list (for example, references used in meta-analysis), it should be so stated in a note, and made available to readers by contacting the author directly. Do not include such a list in the manuscript document, but it may be submitted separately for purposes of review.

Use *only* the 6th edition of the *Publication Manual of the American Psychological Association (APA)* as your source of instruction for references (this is critically important). Translate non-English titles into English (see *APA* for instruction on how to do this). Reference and cite all other studies mentioned in the article. Test all Internet URLs (Web addresses) immediately before submission to ensure that they are accurate, and that the sites are still accessible; do this prior to submission of all revisions and accepted manuscripts, as well.

APPENDICES

Appendices are not encouraged, and are published only at the editor's discretion. If included, appendices should be placed in the main manuscript document following the reference list, and before any tables (place them before the bios in an accepted manuscript). *Appendices must be referred to in the text.*

FINAL CHECKLIST FOR SUBMISSION / COMMON PROBLEMS (removed)

INSTRUCTIONS FOR ACCEPTED MANUSCRIPTS (removed)

SAMPLE MANUSCRIPTS (remove)

MANUSCRIPT REVIEW (removed)

SUBMISSION (removed)

PUBLICATION INFORMATION (removed)

6.4 Appendix D – Research Study Approvals

All identifying information removed and formatting adjusted to assist with presentation

A) Confirmation of Research Ethics Committee (REC) Approval (13.2.13)

Research Ethics Committee

Address

Email address

Miss Catherine Varnell
Trainee Clinical Psychologist
Address

Date 13 February 2013

Your Ref

Our Ref

Enquiries to: Name

Extension: Number

Direct Line: Number

Email:

Dear Miss Varnell

Study title:	Siblings' experiences of having a brother or sister with an eating disorder: a qualitative exploration
REC reference:	XX/XX/XXXX
Protocol number:	Version 2.1 (17/12/12)
IRAS project ID:	xxxxxx

Thank you for your letter of 11 February 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator (name).

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- Reference your letter of 11 February 2013, point 7, please remove the standard clause regarding consent to access medical records for siblings.
- Please spell-check the Patient Information Sheets, to sort out some persisting typos eg "abouta carers group".

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

GP/Consultant Information Sheets Version 1.0 08 February 2013
Investigator CV 10 December 2012
Other: CV - Academic Supervisor 11 December 2012
Other: Interview Schedule & De-brief Version 2 14 December 2012
Other: B-EAT leaflet
Participant Consent Form: 12+ years old affected sibling Version 2.1 17 December 2012
Participant Consent Form: Assent form for parents of children 12-16 Version 1.0 08 February 2013
Participant Consent Form: 12-16 years old non-affected sibling Version 2.2 08 February 2013
Participant Consent Form: 16+ non-affected sibling Version 1 08 February 2013
Participant Information Sheet: 12-16 years old, non-affected sibling Version 2.1 08 February 2013
Participant Information Sheet: 12+ years old, affected sibling Version 2.1 08 February 2013
Participant Information Sheet: 16+ years old, non-affected sibling Version 1 08 February 2013
Participant Information Sheet: Parent- carer of 12-16 year olds Version 1 08 February 2013
Protocol Version 2.1 17 December 2012
REC application 18 December 2012
Response to Request for Further Information 11 February 2013

Statement of compliance The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

XX/XX/XXXX Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee’s best wishes for the success of this project.

Yours sincerely

pp

Dr (Name)

Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

“After ethical review – guidance for researchers”

Copy to: (Name) NHS (health board name) Research and Development Office

B) Confirmation of NHS R&D Approval (18.02.13)

Research & Development

Address

Telephone Number

FM/SS/approval

3rd January 2013 (reissued 18th February 2013)

Miss Catherine Varnell
Trainee Clinical Psychologist
Address

Email:
Director:

Dear Miss Varnell

R&D project number: XXXX/X/XXX/XX

Title of Research: Siblings' experiences of having a brother or sister with an eating disorder: a qualitative exploration

REC reference: XX/XX/XXXX

Documentation:

Protocol: Version 2.1 dated 17 December 2012

I am pleased to inform you that the above study has been approved for NHS (health board) and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS (health board).

Please note that the NHS (health board) R&D office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS (health board). This includes any changes made subsequent to management approval and prior to favourable opinion from the REC.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where appropriate.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely

NAME

Deputy R&D Director

CC: NAME, QA Manager

C) Confirmation of NHS Management Approval for Research Study (20.12.12)

Email confirmation from NAME, NHS Director of Operations

RE: Authorisation for thesis research study to go for R&D approval

From: NAME

Sent: 20 December 2012 11:48

To: Varnell Catherine Jessica

Cc: Name (NHS R&D); Name (NHS R&D)

Apologies I have been away for a few days. I can confirm REAS Management Support for your study. My address etc is below.

Name

(Full Name)

Director of Operations,

NHS (name) Hospital & Associated Services

(phone number)

(email address)

From: NAME

Sent: 11 December 2012 12:35

To: Varnell Catherine Jessica

Subject: RE: Authorisation for thesis research study to go for R&D approval

Hi,

Yes would be me. If you forward the SSI form that will be sufficient. (NAME)

From: Varnell Catherine Jessica

Sent: 11 December 2012 12:20

To: NAME

Subject: Authorisation for thesis research study to go for R&D approval?

Dear NAME,

I am a third year CAMHS trainee clinical psychologist in the process of completing IRAS and R&D forms for the ethics process for my doctoral thesis.

I had a meeting with NAME (Research Governance Coordinator) on Friday where she gave me your contact details as she believed you might be the person I would need to contact about management authorisation of my study prior to R&D approval.

The section on the forms that may be relevant to you is as follows;

23. Authorisations required prior to R&D approval

This section deals with authorisations by managers within the NHS organisation. It should be signed in accordance with the guidance provided by the NHS organisation. This may include authorisation by clinical supervisors, line managers, service managers, support department managers, pharmacy, data protection officers or finance managers, depending on the nature of the research. Managers completing this section should confirm in the text what the authorisation means, in accordance with the guidance provided by the NHS organisation

She thought you may be the person to contact as my study involves Child and Adolescent Mental Health Services across (health board name) including CAMHS at (hospital name), and you were the appropriate person for another Clinical Psychology Trainee doing her project across NHS (health board name) CAMHS. She also asked me to try (NAME), but he replied saying it wasn't him as he works across medical services at (hospital name), not psychiatric/mental health.

Do you think you would be the person to send my forms and documentation to (e.g. consent forms and patient information sheets), then to receive an email to attach to send to R&D to say you'd be happy to support and authorise my study prior to R&D approval, if this was the case?

If you do not think you are the person I should be contacting, please do let me know so I can try to get a different contact from (NAME) at R&D.

Thank you in advance, and if you have any queries please do not hesitate to contact me.

Catherine

Catherine Varnell
Trainee Clinical Psychologist
Address
Phone Number

6.5 Appendix E – Research Information Sheet

All identifying information removed and formatting adjusted to assist with presentation

Information Sheet

Siblings' experience of having a brother/sister with an eating disorder

Researcher: Catherine Varnell

You are being asked if you would take part in a research study. Before you decide if you would like to take part it is important that you know why the research is being done and what will happen.

Please take some time to read the following information carefully and discuss it with anyone you choose. There is also a parent/carer information sheet.

Please call or email me or the independent contact if there is anything that is not clear or if you would like more information.

Thank you for reading this.

What is the purpose of the study?

I would like to find out more about your experiences of having a brother or sister with an eating disorder. To help me do this I would like to meet with you and ask you some questions about your experiences.

Why have I been chosen?

I have asked you to take part because you have a brother or sister with an eating disorder.

Do I have to take part?

- It is up to **you** to decide whether or not to take part.
- You can have at least **24 hours** between reading this information sheet and making your decision.
- If you do decide to take part, I will ask you to sign a Consent Form.
- If you do take part, you can leave the study and ask for your information to be removed at any time (until it has been typed up and included in the study findings) and you **do not** have to give a reason.
- A decision to leave the study, or a decision not to take part, **will not** affect any care or services that you or your brother or sister receives.

What will happen if I agree to take part?

If you agree to take part I would like to meet with you **once** to ask you some questions and listen to what you have to say.

I would find out a day and time and a NHS Child & Adolescent Mental Health (CAMHS) clinic you would like to meet at. I would give you/your family £10 to cover any costs of travelling to this meeting.

The meeting would last around **1 hour** and I only need to meet you **once**.

You can leave the meeting at any time without a reason, and you do not have to answer a question if you do not want to.

The meeting will be recorded so that I can type it up afterwards.

I would let your GP know that you have been involved in the study.

What will happen to the information I give?

The recording of the meeting will be kept in a secure place in a locked cabinet in a locked room in an NHS hospital. When I type it up I will make sure that any personal information that might identify you or your brother/sister is taken out. This will also be kept in a secure place in a locked cabinet in a locked room at the University.

The recording will be destroyed at the latest by the end of the study which should be February 2014. Only the research team have access to this.

When I use the information you give me in the meeting to write about the study findings that might be published, I will not use your name or any information that would let people know it was you. I will also only use parts of what you say, not the whole conversation.

If you became unable to consent during the meeting, we would stop the meeting and I would not ask any more questions. I would still use only the information you had provided up to that point, which would have any personal identifiable information removed.

Will I find out about the findings of the study?

If you would like a summary of the findings from the study once it is finished, please tick the box on the consent form.

Is there anything to be worried about if I take part?

Some people can get upset talking about their experiences. I will try to help you if you become upset. We will stop the meeting if you get too upset. It can be good to talk to your family or friends if you are upset after our meeting. I can also provide you with helpline numbers/websites so you have someone else to speak to or get information from.

If your family require more support following you taking part in the study, your family can discuss this with the NHS worker already involved with your family and/or they can ask the NHS worker already involved about a carers group for eating disorders (NAME) run by CAMHS.

What could be good about taking part?

Some people find it helpful to talk about their experiences and be listened to.

I also hope the study will help NHS staff and parents and other young people to understanding of what it is like to have a brother or sister with an eating disorder. It might help people be able to know how to support and help a sibling too.

Will my information be kept private and confidential?

Any information you give me will be kept private, unless you tell me something that makes me worry about your safety or the safety of someone else. - If that happened, I would have to tell your parent(s) and a professional like your GP. If I was going to do this I would always let you know.

When I use the information you give me in the meeting to write about the study findings, I will not use your name or any information that would let people know it was you. I will also only use parts of our conversation.

Who has checked the study?

This research study has been checked and approved by the Research Ethics Committee.

It also been approved by NHS Research and Development.

Where can I get more information about the study?

If you would like to talk a bit more about this study before deciding whether to take part, you can contact me (Catherine Varnell) on (phone number) or you can email (email address).

If you would prefer to talk to someone who is not part of the research team, then you would be very welcome to contact Dr (name) on (phone number) or email her at (email address)

If you wish to make a complaint about the study please contact:
NHS Complaints Team (address and phone number)

I would like to take part in the study

- If you would like to take part, please tell me this when I contact you to see if you are interested or not. (*I will have already asked your brother or sister if it is ok with them for me to contact you*).
- You can have *at least 24 hours* between reading this information sheet and making your decision.
- There is a Consent Form to sign if you want to take part (and your parent/carer signs an Assent Form to say they support you taking part).
- You can return the Consent Form in person to the clinic, or in the envelope provided, or bring it with you to our agreed meeting time.
- When we meet you will have the chance to ask any more questions.
- If after this, if you still want to take part, and you haven't already signed the Consent Form, you can do this then with me.
- We would then have our conversation at this meeting.

Thank you for reading this

6.6 Appendix F – Consent and Assent Form Templates

All identifying information removed and formatting adjusted to assist with presentation

A) Affected sibling consent to approach sibling form

Consent Form

Siblings' experience of having a brother or sister with an eating disorder

Study Reference No: XX/XX/XXX Researcher: Catherine Varnell

Please read each of the following points carefully and then put your **initials** in the box next to them if you agree. Please ask if you have any questions.

Please initial all boxes

- I have read and understand the information sheet (Version number /date) for the above study. ☐
- I have had the chance to think about the information and ask any questions and I was happy with the answers to my questions. ☐
- I understand there is no pressure for me to agree to my brother(s) /sister(s) be contacted and my decision will not affect my care. ☐
- I agree to my brother(s)/sister(s) being approached to take part in the above study. ☐

My brother's / sister's name:

.....

Other brother's / sister's name if more than one

.....

Your Name

Signature

Date

Person taking consent

Signature

Date

Thank you for your help

B) Unaffected sibling consent form

Consent Form

Siblings' experience of having a brother or sister with an eating disorder

Study Reference No: XX/XX/XXX Researcher: Catherine Varnell

Please read each of the following points carefully and then **initial** the box next to them if you agree. Please ask if you have any questions.

Please initial all boxes

- I have read and understand the information sheet (Version number/date) for the study. ☐
- I have had the chance to think about the information and ask any questions and I was happy with the answers to my questions. ☐
- I understand that that there is no pressure for me to take part. ☐
- I understand that I can leave the study at any time and ask for my information to be removed (*until it has been typed up and included in study findings*) without giving a reason and this will not affect the care I or my brother /sister receives. ☐
- I understand that if I become unable to consent during the meeting, it will be stopped; however, information collected up to that point will still be included in the study findings. ☐
- I agree to my GP being told about me taking part in this study. ☐
- I agree to the meeting being voice recorded and this recording being destroyed by the end of the study (approx. Feb 2014) ☐
- I agree to take part in the above study. ☐
- Initial box if you would like a copy of the summary of study findings. ☐

Name of participant Signature Date

Person taking consent Signature Date

Thank you for your help

c) Parent/carer assent form

Parent/carer Assent Form

Siblings' experience of having a brother or sister with an eating disorder

Study Reference No: XX/XX/XXX Researcher: Catherine Varnell

Please read each of the following points carefully and then **initial** the box next to them if you agree. Please ask if you have any questions.

Please initial all boxes

- I have read and understand the information sheet (Version number /date) for the study. ☐
- I have had the chance to think about the information and ask any questions, and I was happy with the answers to my questions. ☐
- I understand that that there is no pressure for my child to take part. ☐
- I understand that my child can leave the study at any time and ask for their information to be removed (*until it has been typed up and included in study report findings*) without a reason and this will not affect the care they/their sibling receives ☐
- I understand that if my child becomes unable to consent during the meeting, it will be stopped; however, information collected up to that point will still be included in the study findings. ☐
- I understand the meeting with my child being voice recorded and that this recording will be destroyed by the end of the study (approx. Feb 2014). ☐
- I understand that my child's GP will be informed of their participation in the study. ☐
- I support my child's decision to participate in this research project. ☐

Name of parent/carer Signature Date

Person taking consent Signature Date

Thank you for your help

6.7 Appendix G – Interview Schedule including Briefing and Debriefing

Briefing

“Thank you for coming along today. I will start by going back over what we will be doing today, and if you’re happy to go ahead we’ll get started”.

- go over Patient Information Sheet with participant
- checking they have understood (and retained) this information by asking them to verbally explain in their words their understanding of:

1) What they think the purpose/point of the research is?

2) What they think will be involved for them to do, and its benefits/potential risks (other language could be 'pros and cons / positives and negatives)?

3) What will happen if they do or do not choose to go ahead, and if they choose to stop and withdraw (leave) during the interview

- inform the young person of how to withdraw or choose not to answer a question (you can withdraw at any time by saying e.g. “I would like to stop and leave now”, or we could agree a hand signal now so you don’t even have to say anything)

- you can choose not to answer particular questions by saying e.g. “let’s skip that one” or something else you prefer, or again we could agree a hand signal so you don’t have to say anything

Practice this with the participant so he/she feels comfortable in how to utilise this right should they wish to.

(Reiterate) “So as it outlined in the patient information sheet (version number/date) I will be asking some questions about your experiences, but I will mainly be listening to what you have to say. Please take your time in thinking and talking. This is not a test in any way and there are absolutely no right or wrong answers.

You are free to stop at any time, and you can decide not to carry on if you want, also you don’t have to answer certain question if you do not want to – like we just practised.

We will be here for about an hour and the voice recorder (point to it) will record our conversation so I don’t forget what you say. What you say will be kept private, so people will not know it was you who said this, and your name and personal information will be removed when I write this up from the voice recorder. Information you tell me will not be shared, unless you mention something that causes me to worry about you and any risk of harm to yourself or anyone else. If you did I would have to inform your parent(s) and/or possible professions like your GP, but if I had to do this I would let you know.

Do you have any questions at the minute? If you have any questions at any time please feel free to ask them.”

- Are you happy to start (verbal consent)? (if not already done paper consent, go through consent form with them too).

Interview Schedule

General conversation to ease in the young person and try to build rapport, then:

- 1) Can you tell me about who's in your family?
Possible prompts: who lives at home with you/who's around?

Unstructured, open ques – Can you tell me about what it's like to have a brother/sister with an eating disorder?

Semi-structured questions and prompts to guide interview if required:

- 2) Can you tell me about finding out about (*insert your brother / sister or sibling's name*) eating disorder?
Possible prompts: what do you remember? how long ago? What did you think about it? how did you feel?
- 3) What does (*insert your brother /sister or sibling's name*) having an eating disorder mean to you?
Possible prompts: what's it like to be their brother/sister? any words or images come to mind?
- 4) Can you tell me about any support your family have experienced since you found out about their eating disorder?
Possible prompts: what? positives/negatives? how do you feel about it?
- 5) What impact has (*insert your brother / sister or sibling's name*) eating disorder had on you/your life, if any? If needs re-wording – Has (*insert your brother / sister or sibling's name*) having an eating disorder, changed anything for you / in your life?
Possible prompts: family relationships, friends, school, interests? in what way has that changed? (including anything positive/good experienced)? how does that make you feel?
- 6) Is there anything you do to try to relax or help you cope since you found out about (*insert your brother/sister or sibling's name*) eating disorder?
Possible prompts: what sorts of things do you do? how do they make you feel? anything else you think may be useful?

General prompts:

- Could you tell me a little bit more about that?
- You've just mentioned ..., can you give me any examples?
- Can I ask a few more questions about the things you've just said?
- Can I just check I've understood you..., is that right?

General probes:

- What do you mean by ...?
- How do you feel about ...?
- Can you tell me what you were thinking?
- What does that mean to you?

Following the interview

"Now I am going to summarise/go over some of the key areas/things we discussed today to make sure I have understood. If you notice I've got something wrong or you want to add anything else please just say."

Debriefing

"Thank you for coming to talk to me today and for contributing to this study. I really appreciate how you've been able to tell me about your experiences."

"How was it doing this? How do you feel now? Are you feeling ok to leave?"

(Manage any distress with procedure as agreed in protocol)

(Explain nothing further for them to do, if they ticked for summary of findings they will be sent this at the end of the study.)

"Do you have any questions before you leave?"

- Thank again and goodbyes.

6.8 Appendix H – GP Letter Template

All identifying information removed and formatting adjusted to assist with presentation

Catherine Varnell

Trainee Clinical Psychologist

(Address)

(DATE)

Dear Dr (NAME),

Your patient, (NAME), has agreed to take part in a NHS / University research project entitled “*Siblings’ experiences of having a brother/sister with an eating disorder: a qualitative exploration*”, which has been approved by Research Ethics Committee (REF).

Participation in the project involves meeting with me once for around 1-hour to discuss experiences of having a sibling with an eating disorder. It will involve questions such as ‘*what does your sibling having an eating disorder mean to you?*’.

For further information regarding the project please see the attached participant study information sheet (version number).

Should you have any queries regarding the above please do not hesitate to contact me.

Yours sincerely,

Catherine Varnell

Trainee Clinical Psychologist

(Health board and university name)

Supervised by: Dr (Lecturer, University name)
Dr (Clinical Psychologist, NHS name)

6.9 Appendix I – Table 4.2 Recurrence of key (super-ordinate) and sub-themes

As noted previously, all names used are pseudonyms

Table 4.2 Recurrence of key (super-ordinate) and sub-themes

Super-ordinate and sub-themes	1-Tina	2-Katie	3-Craig	4-Victoria	5-Edward	6-Finn	7-Naomi	8-Robert	Present in over half sample?
1.Sibling									
Identity:									
- Who am I and what is my role?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	YES
- Who do I want to be?	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	YES
2. Vulnerable social 'self':									
- Experience of disclosure, stigma & evaluation	Yes	Yes	Yes	Yes	No	Yes	No	Yes	YES
3.Intra and interpersonal coping:									
- Self coping	Yes	Yes	Yes	Yes	No	Yes	No	Yes	YES
- The use of 'others' as support	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	YES
- The use of professional support?	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	YES

6.10 Appendix J – Sample of analysis

As noted previously all names are pseudonyms and non-consecutive pages have been used to minimise the likelihood of any breach of confidentiality

Right margin = initial noting;

(Normal text = Descriptive comments; *Italics* = Linguistic comments; Underlined text = Conceptual and interpretative comments)

Left Margin = developing emerging themes

<p>Internal conflict / ?the torn self?</p> <p>Difficult / uncomfortable sib confidence</p> <p>Burden of confider</p> <p>Fragile relationships</p> <p>Desire to comprehend (phenomenological attitude)</p> <p>ED as cause of anxiety</p> <p>Impact on 'well' sibling and sibling relationship - infiltration of the ED</p> <p>Dual role of sibling</p>		<p>P-It was..... really difficult, because I didn't want to tell my parents in case, I don't know, I felt like I needed to but didn't want R to find out that I was telling my parents stuff.</p> <p>Because I felt like she was telling me stuff and I wanted to understand and know what she was doing and thinking, and didn't want her to stop that as then it might be all in secret.</p> <p>And she would say for example, she she would have have her meal at dinner time and then, we live up beside the (location), so she would go along all the different tracks (on his bike), and she would say I need to lose this amount of weight or I need to do this or need to lose that, or she would start to shout at me if I wasn't going fast enough. And in a way it would be good if she told me that so that I could tell my parents what she was doing or saying so that they could then tell at the meetings she was having.</p> <p>I-Ok</p> <p>P-But at the same time it was obviously affecting me, emm,</p>	<p><i>Hesitant – hard to articulate something very complex.</i></p> <p>Internal struggle – protect self/own needs v protect sib/their needs – torn.</p> <p><u>Role or self in pieces – as a child to parent, as a confidante to sibling, as a parent to self/sibling needs. In middle of parents&sib.</u></p> <p>Desire – to really understand sibling's experience/internal world.</p> <p>Worry – loss of sibling's confidence/trust.</p> <p><u>Secret (vs lies, deceit). Want to stay 'in the loop' – a hidden problem harder to help sib. ? feels like having to play spy/detective?</u></p> <p>A preoccupation with weight</p> <p>Exercise to aid weight loss</p> <p><u>Impact of ED/rules protruding / infringing further than just the sufferer. Impinging on siblings relationship</u></p> <p><u>Spy/double agent role -? Must have been hard to not tell sibling what doing? Lots of pressure from different people.</u></p>	
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Dual role of sibling	P-But at the same time it was obviously affecting me, emm, cause I was obviously thinking about it 24/7, yeah	Impact(cognitively/emotionally)of ED on sib <u>24/7 – phrasing suggests overwhelming, all-encompassing nature for sibling. No space/time for self? Rumination</u>
Excessive thinking Burden of confider	I-So on your mind a lot P -Yeah even with school work and stuff so it was hard...., although I don't think it affected my school work too much as there was a lot of support at school too, cause my parents told the head teacher and my guidance teacher so that helped things a lot, em, they would talk	Importance of support - ?what type of support provided – emotional, practical?

Coping – support from others	to me yeah and check in to see how we were doing and stuff.	<u>Not forgetting about sibling (despite a lot of focus on affected child) – importance to tell school (not secretive)</u>
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Journey to acceptance	too much into it at all, and then	realisation? Stages of change / grief – change
Stages of change (process)	it wasn't until they started going to the hospital that I knew it was obviously quite serious.	management. idea of process of transition
Gradual process-coming to terms with it	I-Ok, so at the time that just sort of...	Acceptance took time – reality sinking in.
Re-formulation	P-Yeah, it didn't really sink in, I didn't really understand what it was, but then we got a diagnosis and information packs and different things and I understood it differently.	Hard to comprehend, usefulness of information/knowledge Construe different perceptions / new understandings of ED at different times/stages – a journey. Re-thinking ED's.
Shared understanding	I-How did it feel getting more information, starting to know more?	Mixed emotions about diagnosis/professional input - solace taken in knowing external help is available v acknowledging the MH problem. MH problems – unknown to family, hard to understand, not know how to help with specifically a MH problem?
Diagnosis - mixed emotions	P-Emm, it was really good because we knew she was, we understood her more, we knew she was going to be getting help. But at the same time it was difficult because we knew that she was mentally ill. So it was hard to see her change from being so happy and so like cheery to being not, so it was difficult for us.	Seeing a family member change for worse before them – how to help/intervene, feeling helpless, useless? How does ED change them too?
Transformation of sibling	I – Mmm (pause) that sounds very hard. (Long Pause). Before having the information, what did you think about an eating	

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